



LOST in INTERPRETATION

The use of ESI Funds during 2014 – 2020
and the impact on the right of persons
with disabilities to independent living



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Written by: Ines Bulić Cojocariu and Nataša Kokić, European Network on Independent Living (ENIL)

Layout: Marieta Vasileva

Cover photo: An institution for persons with disabilities in Upper Austria which has received funding from the European Union
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FOREWORD



Home.

This is probably the single most evocative word in our vocabulary. It gives us the space to be who we are; to grow and to express our sense of self. It is not just or even primarily about bricks and mortar.

It provides the very scaffolding of the self. Its many connections to the community and to the outside world enable us to connect and interact because we are primarily social beings – our personhood is shared. Our doorway invites conversation and interaction. It is these interactions that reinforce who we are and allow us to continually evolve as humans.

One of the many legacies of the past has been the assumption that home is only for the privileged few – that some people including those with disabilities cannot thrive in their own home. It is as if we problematised the person and, by creating institutions, we denied them an opportunity for the free expression of their selves in their own home.

Home doesn't have to be fancy – it just needs to be yours. Stripped of legalise, Article 19 of the UN CRPD is premised on a positive philosophy – that everybody can thrive in home. It affords choice in how one lives in the community – not whether one lives in the community. It points to the revolution that needs to happen in services to make this a reality. And it connects the vision of home with access to services in the broader community.

Over the decades Europe has built a 'common European home' for its citizens. It has equipped itself with the means and the financial instruments to assist its Member States to transition to a more inclusive as well as sustainable social and economic future. The genuine 'additionality' of the EU Structural and Investment Funds enables innovation to happen. This is needed now more than ever. The potential for positive change is enormous.

The gains made in recent years need to be built on. The spirit of the new Regulations as well as their letter needs to be respected. This isn't just about respecting the UN CRPD – which it is. This isn't just about avoiding public health risks like Covid-19 that are inescapably intrinsic to institutions – which it is. It is also about making the dream of a 'common European home' for all meaningful for those who have been left outside the dream for too long.

This Report keeps that dream alive. It helps frame a new policy conversation and imagination. All the essentials are in place. Europe has the potential to lead by example. All its citizens – including its taxpayers – will have reason to be thankful.

Prof. Gerard Quinn

UN Special Rapporteur on the Rights of Persons with Disabilities

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This study was written by Ines Bulić Cojocariu and Nataša Kokić, from the European Network on Independent Living (ENIL). ENIL is a Europe-wide network of persons with disabilities, with members through-

out Europe. ENIL is a forum for all persons with disabilities, 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, deinstitutionalization, democracy, self-representation, cross disability and self-determination. For more information, please go to www.enil.eu.

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INTRODUCTION

In 2014, when the new financial period was beginning, there was a great deal of expectation that the European Union funds would help Member States move away from large segregating institutions for persons with disabilities and facilitate access to the right to live independently in the community. The

reasons for such optimism were many. Among other, there was ample evidence about millions spent on reinforcing institutional care during the 2007 – 2013 programming period.¹ Furthermore, the new regulations for the European Structural and Investments Funds (referred to as ‘ESI Funds’) included, for the first time, “transition from institutional to community-based care” as an investment priority, and twelve Member States² were required to have in place deinstitutionalisation strategies as a precondition for using ESI Funds.

During the 2014 – 2020 programming period, Ireland ratified the UN Convention on the Rights of Persons with Disabilities (CRPD) as the last Member State to do so. This meant that the entire European Union, with all its Member States and as a regional organisation, was now party to this major international treaty. Once again, this should have been a guarantee that no public or private funding would go towards services that restricted or violated the rights of persons with disabilities. The European Disability Strategy 2010 – 2020, which comes to an end this year, also had independent living, and ensuring that ESI Funds supported the transition from institutional to community-based care, as one of its priority areas³.

The aim of this study, commissioned by the European United Left/Nordic Green Left (GUE/NGL) group in the European Parliament, is to highlight the arguments why ESI Funds should be used to support the right of children, adults and older persons with disabilities to live independently in the community. The study also points to the main problems that arose during the 2014 – 2020 period, and which resulted in the ESI Funds contributing to the continued segregation and exclusion of these groups from society.

Methodology and limitations

Information for Chapter III, which details concerns in the Member States during the 2014 – 2020 funding period, was collected by the European Network on Independent Living (ENIL) from organisations of persons with disabilities (DPOs)

1 See, for example: European Parliament, 2016. *European Structural and Investment Funds and People with Disabilities in the European Union, Study for the PETI Committee*. Available from: http://enil.eu/wp-content/uploads/2016/06/COMMITTEES_PETI_2016_11-09_Study-EU-Funds-Disabilities.pdf

2 The twelve Member States where deinstitutionalisation was a priority in 2014 – 2020 were: Bulgaria, Croatia, the Czech Republic, Estonia, Greece, Hungary, Latvia, Lithuania, Poland, Romania, Slovakia and Slovenia.

3 European Disability Strategy 2010-2020: A Renewed Commitment to a Barrier-Free Europe, COM(2010) 636 final, 15 November 2010. Available from: <https://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=COM:2010:0636:FIN:en:PDF>

and other non-governmental organisations (NGOs) active in the “EU Funds for Our Rights Campaign”. This includes the following Member States: Austria, Belgium, Bulgaria, Croatia, the Czech Republic, Estonia, Germany, Greece, Hungary, Lithuania, Poland, Portugal, Romania, Slovakia, Slovenia and Spain.

Due to the lack of capacity of many DPOs and NGOs to monitor the use of ESI Funds, the lack of transparency in the Member States about investment plans, and the projects supported, and the lack of consultation with organisations of persons with disabilities (DPOs) in the Member States, this information is by no means comprehensive. Whereas in some countries, ENIL has been able to obtain detailed information about specific calls or projects, in other countries, there is only anecdotal evidence of how ESI Funds are being used. To date, there is no publicly accessible database, either at the national or European level, with detailed descriptions of projects supported with ESI Funds, which would allow DPOs and NGOs to establish to what extent these projects facilitate the right to live independently and being included in the community.

Overview of the chapters

The study is divided into four chapters, as follows:

- Chapter I:** The first chapter provides a snapshot of the situation in the European Union, with regard to the number of persons with disabilities in institutions, and progress towards independent living since 2014. The situation of persons with disabilities in institutions during the COVID-19 pandemic is also highlighted.
- Chapter II:** The second chapter focuses on the legal basis for investing ESI Funds in independent living. It then examines the question whether investments into institutions (of any kind) are permissible under international and EU law.
- Chapter III:** The third chapter brings together examples of investments during the current programming period (2014 – 2020) and highlights key concerns identified by the disability community. Additional information about specific projects in Austria, Hungary, Bulgaria and Romania is presented in the form of case studies.
- Chapter IV:** The final chapter highlights some considerations for the future, considering that a new programming period begins in 2021 and that Member States have been provided with significant funds to deal with the impact of the COVID-19 pandemic. The recommendations set out in this chapter aim to ensure that no EU funds are used to place persons with disabilities in institutions.

Two annexes – with definitions of the terms used in the study and recommendations for further reading – can be found at the end.

CHAPTER I

Institutionalisation of persons with disabilities in the European Union

1.1. Prevalence of institutionalisation in the European Union

Despite the universal ratification of the UN Convention on the Rights of Persons with Disabilities (CRPD) in the European Union, a 2020 study on the transition from institutional to community-based care in the 27 EU Member States⁴ found that at least 1,438,696 children and adults still live in long-stay residential institutions⁵. This is likely to be an underestimate, because the figure does not include some of the

unaccompanied migrant children living in institutions and older adults, including those with disabilities placed in nursing homes for older people.

Children and adults with intellectual disabilities, autism, people with psychosocial disabilities and those who require high levels of support are particularly affected by institutionalisation. Personal assistance, as a key tool for independent living, has been found to be “a minority form of provision”, in almost all countries.⁶

The same study found that the number of people in institutions has not “substantially changed” over the past 10 years. Similar findings were reported by the Academic Network of European Disability Experts (ANED) in its synthesis report on independent living⁷, which found that despite a gradual shift away from institutions, progress in many countries has slowed down in the last 7 years.

Both studies concluded that Member States’ access to the European Structural and Investment Funds (referred to as ‘ESI Funds’), including for the transition from institutional care to community-based services, has failed to substantially decrease the number of people in institutions and to significantly improve opportunities for children and adults with disabilities to grow up in families and to live independently in the community.

4 Šiška, Jan and Beadle-Brown, Julie, 2020. *Report on the transition from institutional care to community-based services in 27 EU Member States*, European Expert Group on the Transition from Institutional to Community-based Care. Available from: <https://deinstitutionalisationdotcom.files.wordpress.com/2020/05/eeg-di-report-2020-1.pdf> (referred to as “the Šiška study”).

5 The Šiška study covered 27 EU countries and six target groups: adults with disabilities, adults with psychosocial disabilities, children (including children with disabilities), unaccompanied or separated migrant children, homeless persons and older adults.

6 *Ibid*, page 13.

7 Academic Network of European Disability Experts (ANED), 2019. *The right to live independently and to be included in the community in the European States: ANED synthesis report*, page 30. Available from: <https://www.disability-europe.net/theme/independent-living> (referred to as “the ANED report”)

One of the issues highlighted is that many of the “smaller” residential care facilities, built to replace large institutions and in some cases supported with ESI Funds, perpetuate institutional culture and do not allow for the provision of person-centred support and inclusion in the community:

“ There are **many examples of smaller institutions being created and older institutions being reorganised into smaller units but essentially the provision is still a large group of people on one site.** Even with personal budgets/direct payments there were differences in how they could be used – in some countries they could be used to buy places in residential care rather than used for personal assistance to help people live in their own home with support coming into them. Services referred to as “supported living” also varied in model and size with few countries providing supported living arrangements that met the definition or were consistent with the ethos of supported living.”⁸

ANED report went on to suggest how the potential of ESI Funds could be harnessed more successfully to promote independent living in the European Union:

“[...] the potential of the policy and funds to advance independent living could be greatly enhanced **were steps taken to ensure consistency between European Union policy and guidance and the advice of the UNCRPD Committee in General Comment 5 on the right to live independently and to be included in the community.** In particular, adoption of the language contained in Article 19, in place of the language of ‘community-based care’ and greater clarity about the acceptability of congregate modes of care and living would send vital signals to countries in Europe. **Centring policy and associated discourse on increasing the choice, control and participation of persons with disabilities, as opposed to transforming the care system, would be advantageous** and would help to promote investment in measures such as personal assistance schemes and peer support.”⁹

⁸ The Šiška study, page 14.

⁹ The ANED report, page 26.

Throughout the 2014 – 2020 programming period, concerns about “re-institutionalisation” of persons with disabilities in the newly built facilities and services, some of which were supported through ESI Funds, were expressed by international disability organisations, the Committee on the Rights of Persons with Disabilities (referred to as the ‘CRPD Committee’), the Special Rapporteur on the rights of persons with disabilities, the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health and Members of the European Parliament. These concerns are explored in more detail in Chapter III of this study.

1.2. Impact of the COVID-19 pandemic on persons with disabilities in institutions

The ongoing COVID-19 pandemic has exposed and deepened the existing inequalities in the European Union, with persons living in institutional care settings (including social care homes for children and adults, nursing homes and psychiatric institutions) most severely affected. In June, three months after COVID-19 started spreading rapidly around Europe, several EU Member States were reporting large numbers of fatalities in institutions. In Belgium, out of 9,696 deaths, 4,851 were in care homes; in France, out of a total 29,547 deaths, 14,341 were in institutions; while in Spain, a staggering 68,1% of all COVID-19 deaths were in institutional settings¹⁰. Since June 2020, when this data was collected, additional infections and fatalities were reported by the media from institutions for children, adults and older people from all over the European Union.

According to the COVID-19 Disability Rights Monitor (DRM)¹¹, a global survey on the impact of COVID-19 on persons with disabilities, the emergency measures taken by Governments to control the spread of the virus exacerbated pre-existing abuses in institutions for persons with disabilities. The DRM final report noted that people living in institutions were denied access to healthcare, banned from receiving any visits, and have been isolated during outbreaks of COVID-19. Hundreds of testimonies received from persons with disabilities, including from many countries in the EU (such as Germany, Austria, France, Italy and Slovenia), confirmed that, in the 50% of cases, Governments had taken no measures to protect the life, health and safety of persons with disabilities in institutions. Failings were reported when it comes to access to food, basic medical supplies, personal protective equipment, or other measures to minimise infections and to prevent deaths in institutions.

10 International Long-term Care Policy Network, June 2020. *Mortality associated with COVID-19 outbreaks in care homes: early international evidence*. Available at: <https://ltccovid.org/wp-content/uploads/2020/06/Mortality-associated-with-COVID-among-people-who-use-long-term-care-26-June.pdf>

11 COVID-19 Disability Rights Monitor Coordinating Group, 2020. *Disability rights during the pandemic – A global report on findings of the COVID-19 Disability Rights Monitor*, pages 22 – 27. Available from: <https://covid-drm.org/assets/documents/Disability-Rights-During-the-Pandemic-report-web.pdf>

Monitoring the situation in institutional care settings has become even more difficult during the pandemic. Many respondents noted the impact of bans on visits and restrictions on the freedom of movement on mental health of persons with disabilities. A Greek DPO referred to a psychiatric institution as being “hermetically sealed”. Over a quarter of respondents stated that residents of institutions were not informed about the state of emergency or the measures imposed by their Governments.

The impact of COVID-19 on children, adults and older people in institutions has put a spotlight on the need to facilitate access to independent living and being included in the community as a matter of priority, for all persons with disabilities. A call by disability rights groups for ‘emergency deinstitutionalisation’¹² has resulted in the establishment of a working group on deinstitutionalisation by the CRPD Committee in September 2020. The objective of emergency deinstitutionalisation is to urgently move as many people as possible out of institutions, and provide them with personal assistance, housing and other support services, as the only way to protect them from infection with the virus and other abuses.

12 See: <https://enil.eu/news/emergency-deinstitutionalisation-a-joint-call-to-act-now/>

CHAPTER II

Legal basis for investing in the transition from institutions to independent living

2.1. The right to independent living

The right to live independently and to be included in community is set out in Article 19 of the UN Convention on the Rights of Persons with Disabilities (CRPD), ratified by the European Union and all its Member States. Article 19 requires States Parties to the CRPD to ensure that persons with disabilities “have the opportunity to choose their place of residence of where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement”. They must be provided with a range of community-based services “necessary to support living and inclusion in the community, and to prevent iso-

lation or segregation”. Mainstream services and facilities must also be made accessible “on an equal basis to persons with disabilities” and “responsive to their needs”.

Article 19 is “one of the widest ranging and most intersectional articles” and “integral for the implementation of the Convention across all articles”.¹³ The right to independent living applies equally to all persons with disabilities, regardless of how much support they need to be fully included and participate in the society. Thus, the preamble to the CRPD recognises “the need to promote and protect the human rights of all persons with disabilities, including those who require more intensive support”.

Although institutionalisation is not explicitly mentioned in Article 19, General Comment 5 on living independently and being included in the community¹⁴ confirms that independent living implies “life settings outside residential institutions of all kinds.”¹⁵ Moreover, both the Special Rapporteur on the rights of persons with disabilities (see Table 1) and the Special Rapporteur on the right to health (see page 22), as well as the CRPD Committee (see Table 2) have made it clear that institutionalisation is incompatible with independent living:

13 General comment No. 5 (2017) on living independently and being included in the community, paragraph 6. Available from: <http://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=6QkG1d%2fPPRiCAqhKb7yhsnbHatvuFkZ%2bt93Y3D%2baa2q6qfzOy0vc9Qie3KjjeH-3GA0srJgyP8IRbCjW%2fSqmYQHwGkfikC7stLHM9Yx54L8veT5tSkEU6ZD3ZYxFwEgh>

14 It is worth noting that the general comments published by the Committee do not create new obligations, but aim to provide authoritative guidance to States Parties on their obligations under a particular article.

15 General comment 5, paragraph 16c



“Living independently and being included in the community **precludes life in any type of institution, from small-scale group homes to large-scale institutions.** Persons with disabilities should have access to a range of individualized support. States parties should ensure access for all persons with disabilities to accessible mainstream services in the community. States parties should respect the minimum core elements of article 19.”¹⁶

Pursuant to Article 216(2) of the Treaty on the Functioning of the European Union (TFEU), “[a]greements concluded by the Union are binding upon the institutions of the Union and on its Member States.”¹⁷ Thus, Article 19 of the CRPD, as interpreted by the General Comment 5, creates a legal obligation for the European Union and the Member States, including the European Commission. Pursuant to Articles 4 and 6 of the Regulation 1303/2013 on the common provisions for the European Structural and Investment Funds¹⁸, operations supported by ESI Funds shall comply with EU law, including its obligations under the CRPD. Moreover, Article 7 of the Common Provisions Regulation states that “the Commission shall take appropriate steps to prevent discrimination”, including that based on disability, during the preparation and the implementation of an ESI funded programme.

16 Committee on the Rights of Persons with Disabilities, Inquiry concerning Hungary under article 6 of the Optional Protocol to the Convention, CRPD/C/HUN/IR/1, 17 September 2020, paragraph 100. Available from: <http://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=6QkG1d%2fPPRiCAqhKb7yhnsbHatvuFkZ%2bt93Y3D%2baa2q6qfzOy0vc9Qie3KjjeH-3GA0srJgyP8IRbCjW%2fiSqmYQHwGkfikC7stLHM9Yx54L8veT5tSkEU6ZD3ZYxFwEgh> (referred to as “UN Inquiry on Hungary”)

17 Treaty on the Functioning of the European Union, see: <https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=celex%3A12012E%2FTXT>

18 European Union 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 Cohesion Fund and the European Maritime and Fisheries Fund and repealing Council Regulation (EC) No 1083/2006. Available from: <https://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=CELEX:32013R1303&from=LV>

Table 1: CRPD articles which prohibit the placement of persons with disabilities in institutions¹⁹

Institutionalisation as a prima facie form of discrimination (Article 5)	<ul style="list-style-type: none"> ➤ Segregation and separate treatment in residential institutions constitute a prima facie form of discrimination and are a breach of the right to non-discrimination. ➤ Institutionalisation is discriminatory as it demonstrates a failure to create support and services in the community for persons with disabilities. Because of this, persons with disabilities are forced to relinquish their participation in the community life to receive services. ➤ Justifications for institutionalisation are based on the medical model of disability, i.e. the view that persons with disabilities need “specialised care” provided in institutions.
Institutionalisation is contrary to the right to live independently in the community (Article 19)	<ul style="list-style-type: none"> ➤ The right to live independently in the community entails living outside residential institutions of all kinds. ➤ Persons with disabilities cannot exercise choice when there is a lack of options to choose from: for example, where support is unavailable outside institutions, or where support is provided only within specified forms of residence such as group homes or small institutions. ➤ The development of small institutions cannot be part of a deinstitutionalisation process and represents a regressive measure in relation to a state’s obligations with respect to the right to live independently in the community.
Institutionalisation is contrary to the right to family life (Article 23)	<ul style="list-style-type: none"> ➤ The right to live in the community is intimately linked with the right to family life. ➤ Where the immediate family is unable to care for a child with disabilities, States parties must undertake every effort to provide alternative care within the wider family, and failing that, within the community in a family setting. ➤ Article 23 CRPD standards are higher than those established in the Convention on the Rights of the Child and other international instruments, given the widespread practice of institutionalisation of children with disabilities, who are denied the right to grow up in their families.

¹⁹ This is a summary of key points made by the Special Rapporteur on the rights of persons with disabilities and the Special Rapporteur on adequate housing as a component of the right to an adequate standard of living, and on the right to non-discrimination in this context, in a communication addressed to President of the European Commission Ursula von der Leyen, dated 18 May 2020 (OTH 38/2020). The communication focused on the misuse of ESI Funds for institutionalisation in the 2014 – 2020 programming period. Available from: <https://sp-commreports.ohchr.org/TMResultsBase/DownloadPublicCommunicationFile?gId=25267>

Institutionalisation as a form of deprivation of liberty (Article 14)

- Institutional environments breed cultures of violence, stigmatization and helplessness, which can be conducive to physical, sexual and other forms of abuse.
- Article 16 affirms the State’s obligation to protect persons with disabilities from all forms of exploitation, violence and abuse, including their gender-based aspects.
- Institutionalisation further reinforces a vicious cycle of inequality and social exclusion, preventing the exercise of rights such as education, work and political participation.

International cooperation must support the realisation of human rights (Article 32)

- International assistance, including ESI Funds, should not support practices contrary to the human rights-based approach to disability.
 - The European Commission, as part of its international obligations, including the Charter of Fundamental Rights of the EU, should refrain from supporting projects that violate the rights of persons with disabilities, such as the development or maintenance of institutions.
 - Providing adequate support to persons with disabilities is a much more successful and cost-effective option than putting them in institutions of any kind.
-

2.2. Deinstitutionalisation as an investment priority during 2014 – 2020

In preparation for the 2014 – 2020 programming period, and based on the lessons learned during 2007 – 2013, the European Commission took a number of measures to encourage the use of ESI Funds to promote the transition from institutional care to community living. Mainly, this was done through the revision of the regulations and by supporting the development of guidance for Member States.

An example of this has been the introduction of general and thematic ‘ex ante conditionalities’ in the Common Provisions Regulation²⁰, which required certain conditions to be fulfilled before Member States could use the funds. Whereas the general ‘ex ante conditionality’ related to administrative capacity for the implementation of the CRPD, one of the thematic conditionalities related to deinstitutionalisation. Thus, twelve Member States where deinstitutionalisation was identified as a priority²¹ were required to demonstrate that the “national strategic policy framework for poverty reduction” includes “measures for the shift from institutional to community-based care”.²²

²⁰ European Union Regulation (EU) No 1303/2013, see Footnote 18.

²¹ This specific requirement applied to Bulgaria, Croatia, Czech Republic, Estonia, Greece, Hungary, Latvia, Lithuania, Poland, Romania, Slovenia and Slovakia.

²² European Union Regulation (EU) No 1303/2013, Annex XI – Ex ante conditionalities, see Foot

Guidance on ex ante conditionalities issued by the European Commission in the Draft Thematic Guidance Fiche for Desk Officers: Transition from Institutional to Community-based Care (Deinstitutionalisation) ('the Thematic guidance') described such measures as including "the development of services based in the community enabling people to live independently and preventing the need of institutionalisation".²³

On the question of whether there is explicit prohibition of investing ESI Funds into institutions, the regulations and guidance from the European Commission made it clear that ESI Funds must not be invested in institutional care.²⁴ For example, in its initial report to the CRPD Committee, the European Commission explained that:

“Promoting the transition from institutional to community-based services is one of the investment priorities of the European Regional Development Fund (ERDF). [...] The **ERDF should as a basic principle not be used for building new residential institutions or the renovation and modernisation of existing ones.** Targeted investments in existing institutions can be justified in exceptional cases where urgent and life-threatening risks to residents linked to poor material conditions need to be addressed, but only as transitional measures within the context of a deinstitutionalisation strategy.”²⁵

The European Parliament has also, in its activities, promoted the use of ESI Funds for improving access to CRPD rights, including independent living²⁶.

23 European Commission, *Draft Thematic Guidance Fiche for Desk Officers: Transition from Institutional to Community-based Care (Deinstitutionalisation)* ('the Thematic guidance') Version 2 – 27/01/2014.

24 See European Expert Group on the Transition from Institutional to Community-based Care, 2014. *Toolkit on the Use of European Union Funds for the Transition from Institutional to Community-based Care: Revised edition*, page 24. Available from: <https://enil.eu/wp-content/uploads/2016/09/Toolkit-10-22-2014-update-WEB.pdf>

25 European Commission, *Report on the implementation of the UN Convention on the Rights of Persons with Disabilities (CRPD) by the European Union' (SWD(2014)0182)*, Annex A.4.4, paragraph 98.

26 See, for example, the following written questions by Members of the European Parliament in 2017 – 2019. On Article 19 and the use of ESI Funds: https://www.europarl.europa.eu/doceo/document/E-8-2019-000912_EN.html; on the situation in Portugal: https://www.europarl.europa.eu/doceo/document/E-8-2018-006110_EN.html; on the situation in France: https://www.europarl.europa.eu/doceo/document/E-8-2018-005353_EN.html; on the monitoring and complaints system: https://www.europarl.europa.eu/doceo/document/E-8-2017-002540_EN.html.

For example, the 2019 European Parliament Resolution²⁷ on the occasion of the 30th anniversary of the Convention on the Rights of the Child calls on the European Commission “to use EU funds to support the transition from institutional to community-based services, both inside and outside the EU.” In February 2020, the Petitions Committee of the European Parliament held a hearing in the complaint brought by the Centre for Independent Living Sofia, ENIL, the Bulgarian Helsinki Committee and the Validity Foundation, concerning the planned use of ESI funds for the building of smaller institutions for persons with disabilities and older people in Bulgaria.²⁸ The petition remains open.

Despite the Commission regulations, guidance and the work of the Parliament, many Member States continued investing ESI Funds into institutions, or failed to make significant progress with deinstitutionalisation reforms (see Chapter III for a list of the main concerns identified during 2014 – 2020).

2.3. Application of the EU Fundamental Rights Charter on the use of ESI Funds

Article 26 of the EU Charter on Fundamental Rights (‘Charter’)²⁹ 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 prohibits any discrimination based on different grounds, including disability, while Articles 24 and 25 concern, respectively, the right of the child to grow up in a family and the right of older persons to a life of dignity, independence and participation in social and cultural life.

The European Ombudsman considered the application of the Charter when pursuing her own-initiative inquiry on the use of EU Funds in 2015, finding that “the Commission is obliged to respect the Charter in its entirety, in all its activities, including in the distribution and monitoring of ESI Funds”. The Ombudsman issued a number of recommendations on how to ensure compliance with the Charter. She noted that “the Commission should not allow itself to finance, with EU money, actions which are not in line with the highest values of the Union [...] the rights, freedoms and principles recognised by the Charter.”³⁰

27 European Parliament resolution on children’s rights on the occasion of the 30th anniversary of the Convention on the Rights of the Child (2019/2876(RSP)), see: http://www.europarl.europa.eu/doceo/document/B-9-2019-0180_EN.html?redirect

28 See: <https://enil.eu/news/petition-on-bulgarias-segregation-of-disabled-people-gets-heard-in-the-parliament/>

29 Charter of Fundamental Rights of the European Union 212/C 326/02, available from: <https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX:12012P/TXT>

30 Decision of the European Ombudsman closing her own-initiative inquiry OI/8/2014/AN concerning the European Commission, European Ombudsman (2015) (referred to as “Ombudsman’s own initiative inquiry”). Available from: <https://www.ombudsman.europa.eu/en/decision/en/59836>

Among other, the European Commission was asked to:

- Include, in its assessment of the success of programmes and actions financed through ESI Funds, consideration of how they have contributed to the promotion of respect for the fundamental rights enshrined in the Charter.
- Consider maintaining, in addition to the new system of complaint-handling, the practice of initiating infringement proceedings against a Member State if its actions in the framework of the cohesion policy amount to a violation of EU law, including the Charter.
- Create a clear and transparent framework in which civil society can contribute to the Commission's supervisory role, in addition to the existing working and expert groups and committees.

As a result of the decision by the European Ombudsman in the own-initiative inquiry, the European Commission published guidance, in 2016, on ensuring respect for the Charter when using ESI Funds, including in relation to “equality before the law, non-discrimination [...] the rights of the child, the rights of the elderly, integration of persons with disabilities”.³¹ This guidance includes a checklist on how to assess compliance with the Charter – a “Fundamental Rights Checklist”. When referring to “the principle of integration of persons with disabilities” the guidance notes that the EU is a party to the CRPD and emphasises the need to ensure compliance with this treaty, as well as the Charter, when managing ESI Funds.

“Regarding the integration of persons with disabilities (Article 26 Charter), EU ratified the UN Convention on the Rights of Persons with Disabilities (UNCRPD) in December 2010. Hence **the UNCRPD forms an ‘integral part of the European Union legal order’**. Furthermore, **international agreements concluded by the European Union have primacy over instruments of secondary law**. Thus, the latter must be interpreted in a manner that is consistent with the UN CRPD.”³²

31 Guidance on ensuring the respect for the Charter of Fundamental Rights of the European Union when implementing the European Structural and Investment Funds. Available from: [http://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=CELEX:52016XC0723\(01\)&from=EN](http://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=CELEX:52016XC0723(01)&from=EN)

32 *Ibid*, at C269/4 and Annex II.

2.4. Prohibition of investing in long-stay residential institutions

One of the key questions addressed during the 2014 – 2020 programming period has been whether there were any circumstances in which Member States may invest ESI Funds into institutions. In this regard, the Legal Service opinion³³, issued by the European Commission in June 2018 and addressed *internally*³⁴ to DG Employment, Social Affairs and Inclusion (DG EMPL) and DG Regional and Urban Policy (DG REGIO), advised that investments into long-stay institutions were permitted, as long as the Member State in question made “progress in general on ensuring independent living and deinstitutionalisation”, that such support was embedded in the “transition process from institutional to community-based care” and in cases of residential institutions “for persons requiring constant care and medical supervision”.

This legal opinion contradicted earlier guidance published by the European Commission, quoted above, and re-interpreted European Union’s and the Member States’ obligations under the CRPD (see Table 1). It was also contested by the Committee on the Rights of Persons with Disabilities in a letter addressed to President Juncker³⁵, and the Committee jurisprudence (see Table 2), by the UN special procedures and legal experts. Finally, the internal legal opinion was also the subject of a complaint to the European Ombudsman, submitted by the European Network on Independent Living (case 1233/2019/MMO).

2.4.1. The question of “progressive realisation”

On the question of whether “progressive realisation” of economic, social and cultural rights³⁶ allowed Member States to invest in institutions during the process of transition from institutional care to independent living, the CRPD Committee and legal experts³⁷ are unanimous in finding that such investments would amount to a regression of rights.

33 European Commission Legal service, Ref. Ares(2018)3471732-29/06/2018.

34 The legal opinion was obtained from the European Commission through a Freedom of Information request.

35 Letter by Theresia Degener, Chair of the Committee on the Rights of Persons with Disabilities to President Juncker, 10 December 2018, Reference: CRPD/2018/HP/CC

36 The concept of “progressive realisation” refers to the State Parties’ obligation to take appropriate measures towards the full realisation of economic, social and cultural rights to the maximum of their available resources. Article 4(2) of the CRPD refers to concept ‘progressive realisation’. See: UN OHCHR, Frequently Asked Questions on Economic, Social and Cultural Rights, available at: <https://www.ohchr.org/Documents/Publications/FactSheet33en.pdf>

37 Quinn, G. et al, 2018. Legal Memore. Segregation and segregated facilities as a prima facie form of discrimination. Available from: <http://enil.eu/news/segregation-and-segregated-facilities-as-a-prima-facie-form-of-discrimination/>

“States parties are under an **immediate obligation to eliminate discrimination against individuals or groups of persons with disabilities and to guarantee their equal right to living independently and participation in the community.** This requires States parties to repeal or reform policies, laws and practices that prevent persons with disabilities from, for example, choosing their place of residence, securing affordable and accessible housing, renting accommodation or accessing such general mainstream facilities and services as their independence would require.”³⁸

It follows that downsizing from large institutions of 100 or 200 people, for example, to smaller institutions of 10, 20 or 40, over a certain period of time, is not permissible; even when these are presented as “temporary” or “half-way” solutions.

2.4.2. Jurisprudence of the Committee on the Rights of Persons with Disabilities

In reviewing progress that States Parties have made in the implementation of their CRPD obligations, the CRPD Committee has made a series of recommendations relevant to the use of ESI Funds, and public funds in general (see Table 2). In this respect, the Committee has been consistent in applying the requirement laid out in the General Comment 5, according to which States Parties to the CRPD must not use public or private funds to maintain, renovate, establish, build or create any form of institutions or institutionalisation.³⁹ Among other, the Committee has asked EU Member States not to replace large institutions with smaller institutions, to redirect funds from institutions to community-based services, and to fund services that promote access to independent living, such as personal assistance.

In 2020, the CRPD Committee found Hungary to be responsible for grave and systematic violations of the CRPD, including of the right to live independently and to be included in the community (see also page 28). The Committee examined the role that ESI Funds have played in expanding the system of institutional care. The report, which explored in detail the characteristics of new “supported housing” services built to replace large institutions for persons with disabilities, found that:

38 General Comment 5, paragraph 46.

39 General Comment 5, paragraph 51.

“Official statistics reveal that public budget allocated for persons with disabilities in the social sector prioritizes provision of specialized social services in institutions, comes primarily from the European Structural and Investment Funds, and is not developing community-based support for independent living compliant with article 19 of the Convention.”⁴⁰

One of the recommendations of the UN inquiry on Hungary, which has implications for other Member States in receipt of ESI Funds, was that investments of human, financial and technical resources should be reoriented “from “supported housing” and other institutional settings, to the development and availability of accessible housing options for persons with disabilities in the community, in all regions across the country, and outside any form of congregate living arrangement.”⁴¹

Table 2: Recommendations under Article 19 CRPD relating to the use of ESI Funds and public funds in general⁴²

Country	Recommendation (i.e. the Committee urges the State party to):
Belgium CRPD/C/BEL/CO/1	The Committee recommends that the State party work towards deinstitutionalization by reducing investment in collective infrastructure and promoting personal choice.
Bulgaria CRPD/C/BGR/1	Significantly expedite the transition process ensuring all persons with disabilities living in any form of institution, including psychiatric hospital units, and small community-based group homes, the right to and possibility of living independently within the community, paying particular attention to persons with psychosocial disabilities, intellectual disabilities, children with disabilities, and elderly persons with disabilities. Use financial national and international resources from the European Union to advance inclusion of persons with disabilities in society, and introduce efficient remedies and guidelines to avoid spending national and international funds on establishing infrastructure, housing and/or services which are not accessible and affordable for all persons with disabilities.

40 UN Inquiry on Hungary, paragraph 72.

41 UN Inquiry on Hungary, paragraph 114(iii).

42 International Disability Alliance, Compilation of the CRPD Committee’s Concluding Observations (as of December 2019). Available from: <https://www.internationaldisabilityalliance.org/resources/compilation-crpd-committee’s-concluding-observations>

Country	Recommendation (i.e. the Committee urges the State party to):
Cyprus CRPD/C/CYP/CO/1	Redirect resources allocated to institutionalization and earmark and allocate them to community-based services and increase the budget enabling persons with disabilities to live independently across the State party with access to individually assessed and adequate services, including personal assistance, within the community.
Czech Republic CRPD/C/CZE/CO/1	The Committee urges the State party to step up the process of deinstitutionalization and to allocate sufficient resources for development of support services in local communities that would enable all persons with disabilities, regardless of their impairments, gender or age, to choose freely with whom, where and under which living arrangements they will live, in line with the provisions of article 19 of the Convention.
Denmark CRPD/C/DNK/CO/1	The Committee recommends that the State party end the use of State-guaranteed loans to build institution-like residences for persons with disabilities; that it amend the legislation on social services so that persons with disabilities may freely choose where and with whom they live, while enjoying the necessary assistance to live independently; and that it take measures to close existing institution-like residences and to prevent the forced relocation of persons with disabilities, in order to avoid isolation from the community.
European Union CRPD/C/EU/CO/1	The Committee recommends that the European Union develop an approach to guide and foster deinstitutionalisation, to strengthen the monitoring of the use of ESI Funds – to ensure they are being used strictly for the development of support services for persons with disabilities in local communities and not the re-development or expansion of institutions. It further recommends that the European Union suspend, withdraw and recover payments if the obligation to respect fundamental rights is breached.
Germany CRPD/C/DEU/CO/1	Allocate sufficient financial resources to facilitate de-institutionalisation and promote independent living, including increased financial resources to provide community-based outpatient services providing the required support to persons with intellectual or psychosocial disabilities based on the free and informed consent of the individual concerned across the whole country.
Hungary CRPD/C/HUN/CO/1	The Committee further calls upon the State party to re-examine the allocation of funds, including the regional funds obtained from the EU, dedicated to the provision of support services for persons with disabilities, and the structure and functioning of the small community living centres, and ensure the full compliance with the provisions of article 19 of the Convention.
Italy CRPD/C/ITA/CO/1	The Committee recommends that the State party implement safeguards to retain the right to autonomous independent living across all regions, and redirect resources from institutionalization to community-based services and increase budget support to enable persons with disabilities to live independently across the country and have equal access to services, including personal assistance.
Latvia CRPD/C/LVA/CO/1	Reinforce the engagement of municipalities in implementing the deinstitutionalization strategy, including through raising awareness about independent community-based living for persons with disabilities and ensuring sustainable provision of services to promote independent living following termination of European structural funds.

Country	Recommendation (i.e. the Committee urges the State party to):
<p data-bbox="188 365 316 398">Lithuania</p> <p data-bbox="172 416 389 450">CRPD/C/LTU/CO/1</p>	<p data-bbox="497 365 1425 465">The Committee is concerned that the national budget and European Union structural funds have been used in renovating existing institutional facilities and in constructing new ones.</p> <p data-bbox="497 488 1425 622">The Committee recommends that the State party further prioritize investing in a social service system for independent living in the community, and immediately refrain from using national and structural funds of the European Union to renovate, maintain or construct residential institutions for persons with disabilities.</p>
<p data-bbox="188 640 284 674">Malta</p> <p data-bbox="172 692 389 725">CRPD/C/MLT/CO/1</p>	<p data-bbox="497 640 1425 775">Ensure that all projects supported by public funds are carried out in a community setting, do not contribute to seclusion of persons with disabilities, are monitored by organizations of persons with disabilities, and are provided with sustainable continuous funding.</p>
<p data-bbox="188 797 284 831">Poland</p> <p data-bbox="172 848 373 882">CRPD/C/POL/C/1</p>	<p data-bbox="497 797 1425 965">Design and adopt concrete action plans for deinstitutionalisation and a time bounded transition to independent living schemes for persons with disabilities within the community, and ensure that adequate funding is allocated to this process after termination of European Union funds allocated specifically for this purpose.</p> <p data-bbox="497 987 1425 1189">Ensure spending of the European Union funds allocated for deinstitutionalisation on measures that is consistent with the Convention; as well as monitoring of spending of the European Union funds allocated for deinstitutionalisation, with the effective participation of persons with disabilities and/or their representative organisations, to ensure that spending is in line with requirements of persons with disabilities themselves.</p>
<p data-bbox="188 1211 300 1245">Portugal</p> <p data-bbox="172 1263 389 1296">CRPD/C/PRT/CO/1</p>	<p data-bbox="497 1211 1425 1480">The Committee recommends that the State party, in close consultation with representative organisations of persons with disabilities, adopt a national strategy for independent living, including increased investment in living independently in the community rather than in institutions, regulate in the field of personal assistance, and offer wider access to sign language interpreters and deafblind sign language interpretation in its public services. Furthermore, the Committee urges the State party to establish community-based support services for persons with intellectual and psychosocial disabilities.</p>
<p data-bbox="188 1503 300 1536">Slovakia</p> <p data-bbox="172 1554 389 1588">CRPD/C/SVK/CO/1</p>	<p data-bbox="497 1503 1425 2020">The Committee recommends that the State party provide and implement a timetable to ensure that the implementation of the deinstitutionalization process is expedited, including by putting in place specific additional measures to ensure that community-based services are strengthened for all persons with disabilities, in particular women with disabilities and older persons with disabilities. Furthermore, the State party should ensure that the use of European structural and investment funds complies with article 19 and that new follow-up national action plans on the transition from institutional settings to community-based support are initiated with the comprehensive involvement of organizations of persons with disabilities and civil society organizations, including in the area of monitoring. The Committee also recommends that the State party no longer allocate resources from the national budget to institutions and that it reallocate resources into community-based services in accordance with the investment priorities of the European Regional Development Fund (art. 5.9 (a) of European Union regulation No. 1303/2013).</p>

Country	Recommendation (i.e. the Committee urges the State party to):
Slovenia CRPD/C/SVN/CO/1	Prevent any form of trans- and re-institutionalisation, and provide sufficient funding for developing community-based independent living schemes.
Spain CRPD/C/ESP/CO/2-3	Discontinue the use of public funds for building residential institutions for persons with disabilities and invest in independent living arrangements in the community as well as in all general services to make them inclusive, guaranteeing their accessibility and availability for all persons with disabilities, to enable their inclusion and participation in all spheres of life.
United Kingdom CRPD/C/GBR/CO/1	Provide adequate, sufficient earmarked funding to local authorities and administrations, including the devolved governments, to be able to continuously allocate adequate resources allowing persons with disabilities to live independently and be included in the community and to exercise their right to choose their place of residence and where and with whom to live.

2.4.3. Communications by the UN Special Procedures to the European Commission

In May 2020, the Special Rapporteur on the rights of persons with disabilities and the Special Rapporteur on adequate housing, sent a letter (also referred to as a ‘communication’⁴³) to the European Commission President Ursula von der Leyen, raising concerns about the “inappropriate use of European Structural and Investment Funds (ESIFs) to maintain institutional care, including by replacing large institutions for persons with disabilities with smaller institutions in several countries of the European Union.”⁴⁴

The communication referred to specific projects in Portugal, Bulgaria, Romania, Hungary and Lithuania, where ESI Funds have been invested in the renovation or building of new institutions for persons with disabilities. It called on the European Commission to:

“[...] implement **robust policies to stop funding that is used to build smaller institutions for persons with disabilities and to ensure that EU funding is used in line with human rights norms and standards.** ESIFs should be used to support the initiation, acceleration and completion of deinstitutionalization strategies and transition to community-based solutions in EU countries.”

⁴³ Special procedures mechanisms can intervene directly with Governments on allegations of violations of human rights that come within their mandates by means of letters which include urgent appeals and other communications. The intervention can relate to a human rights violation that has already occurred, is ongoing, or which has a high risk of occurring.

⁴⁴ See: <https://spcommreports.ohchr.org/TMResultsBase/DownloadPublicCommunication-File?gld=25267>

Similar concerns have been highlighted by the Special Rapporteur on health, in his March 2020 letter to the European Commission.⁴⁵ This communication focused on developments in Bulgaria, where ESI Funds had been approved for replacing large institutions for persons with disabilities and older people with smaller institutions “without addressing the deeply ingrained discrimination, social exclusion and segregation of these groups.” Noting that persons with disabilities must be provided with access to health services as close as possible to their own communities, of the same quality as for others, the Special Rapporteur stated that “the European Commission has a clear responsibility as a donor not to finance initiatives that are contrary to human rights.”

2.4.4. Position of the European Ombudsman on investments in institutions

In addition to her own-initiative inquiry on the use of ESI Funds, the European Ombudsman Emily O’Reilly has dealt with two other complaints concerning investment of ESI Funds into institutions for persons with disabilities.

In a complaint brought by the European Network on Independent Living (case 1233/2019/MMO⁴⁶), closed in July 2020, the Ombudsman has looked into evidence of investment in institutions for persons with disabilities in Hungary and Portugal. In her decision, the Ombudsman found it “difficult to comprehend” the European Commission’s justification for investing in institutions, as long as they do not obstruct progress towards independent living and deinstitutionalisation. She stated:

“It seems obvious that EU funds spent maintaining, or worse still building, institutions **cannot but obstruct progress** on ensuring deinstitutionalisation.”

While recognising that the Commission has taken steps to engage with both the Hungarian and Portuguese authorities, the Ombudsman stated that, when it comes to Hungary, “it is not clear why the Commission did not seek to suspend funds once problems were identified”. She welcomed the fact that, in view of lessons learned, the second call for proposals (which would have resulted in the building of more institutions) was suspended and that the Commission has taken further actions to address the problems that were identified. Recalling that the Commission has made it easier for Member States to access funds to address the COVID-19 pandemic, the Ombudsman highlighted the need to ensure that “those funds are used to uphold the rights of the most vulnerable citizens, in particular the elderly and persons with disabilities”.

45 See: <https://spcommreports.ohchr.org/TMResultsBase/DownloadPublicCommunication-File?gId=25091>

46 Case 1233/2019/MMO, see: <https://www.ombudsman.europa.eu/en/decision/en/119185>

In an earlier complaint (case 417/2018/JN⁴⁷), brought by the Validity Foundation and closed in September 2019, the Ombudsman looked into investment of ESI Funds in the *Topház* social care home in Hungary, where serious human rights abuses were uncovered by the same organisation. In this case, ESI Funds were used to renovate the institution. Having found serious shortcomings in how this case was dealt with by the Commission, the Ombudsman made three recommendations. The Commission was asked to:

- seek to adhere, to the greatest extent possible, to the UN CRPD Committee’s guidance that EU funds should not be used to maintain existing institutions;
- consider the need to address the lack of an appropriate legal basis to ensure that the spending of EU funds complies fully with the UN CRPD;
- monitor the extent to which the Hungarian authorities adhere to the deinstitutionalisation process [...].

47 Case 417/2018/JN, see: <https://www.ombudsman.europa.eu/en/decision/en/130886>

CHAPTER III

Lessons learned during 2014 – 2020

Based on the information gathered by organisations of persons with disabilities (DPOs) and non-governmental organisations advocating for the rights of persons with disabilities in countries covered by this study (see Methodology), six main concerns have been identified. Where good practices were noted, they are mentioned as well.

1. Replacing large institutions for adults with disabilities with smaller institutions
2. Failure to invest into community-based services, such as personal assistance, and accessible housing
3. Replacing large institutions for children with disabilities with smaller institutions
4. Lack of progress with deinstitutionalisation
5. Building and renovation of large institutions, in some cases under the pretext of improving “energy efficiency”
6. Lack of involvement of organisations of persons with disabilities (DPOs)

3.1. Replacing large institutions for adults with disabilities with smaller institutions

Summary of the issue: In most of the Member States which have had “transition from institutional to community-based care” as a funding priority, and some which did not, persons with disabilities have been moved from large into smaller institutions. Such facilities are referred to as group homes, small group homes, supported housing, protected or sheltered housing, independent living centres and other names. According to information available to ENIL, in 2014 – 2020, this has been the case for Austria, Bulgaria, Croatia, the Czech Republic, Estonia, Hungary, Lithuania, Poland, Portugal, Romania and Slovenia.

In **Estonia**, the process of closing down large Soviet-style institutions and building smaller, “family-like” institutions started in the previous funding period and continued during 2014 – 2020. The new institutions accommodate up to 30 persons with disabilities, and are considered by the authorities to be a “necessary” step in the transition from the large settings. A total of 1,400 places have been created in the new facilities since 2014. In addition to the new residential facilities, day care centres and sheltered workshops are being developed for the residents. Those who require less support are being provided with accessible housing in the community and community-based support. However, some may first have to move into the smaller institutions, before they can access housing in the community.

In **Portugal**, the European Regional Development Fund (ERDF) was used to co-fund the building of a new institution for 16 persons with disabilities in Azores⁴⁸, and in several other locations. These include: the reconstruction and refurbishment of a residential home on Victoria Beach in Azores⁴⁹; projects to reconstruct existing institutions for persons with disabilities in the region of Alentejo⁵⁰ and the building of a residential home that provides housing for people with disabilities who are temporarily or permanently prevented from living in their family environment in Madeira⁵¹. ENIL has called on the European Commission to urge the Portuguese authorities to redirect funding into the much needed community-based services, in line with the CRPD. At the moment, the EU funded segregated settings are often the only alternative for people in need of a high level of support and will have a negative impact on their social inclusion, by removing them from their family and community, and reducing their opportunities for participation.

In **Lithuania**, out of 241,861 persons with disabilities, almost 6,500 people (including children and people of retirement age) live in social care institutions. As part of the process of “deinstitutionalisation”, the responsible Ministry plans to move 2,700 – 3,000 persons with disabilities from social care institutions into group homes and other small institutions. In order to “create a home environment” for these individuals, the government has designated 26,5 mil Euro of ESI Funds and 6 mil Euro from the state budget. Thus, almost 33 mil Euro have been allocated to move up to 3,000 persons with disabilities from larger to smaller institutions. The remaining 238,861 persons with disabilities living the community continue to be cared for by their families, without any financial support or personal assistance – for which no funding has been made available.

Case studies from **Austria** (see below), **Bulgaria** (see page 31), **Romania** (see page 35) and **Hungary** (see page 28) provide a more detailed account of the process of replacing large institutions with smaller institutions, with investment from ERDF.

Austria: Institutions and sheltered workshops funded through the European Agricultural Fund for Rural Development (EAFRD)

In July 2020, ENIL and Independent Living Austria (ILA) submitted a complaint⁵² against the State Government of Upper Austria for using the European Agricultural Fund for Rural Development (EAFRD) to build six segregated living facilities and two sheltered workshops for adults with disabilities. The newly built facilities have the following characteristics:

1. A new living unit accommodating persons with high support needs, situated in a large residential facility with about 200 places for children and adults with disabilities;

48 This project can be found under reference number Acores 09-4842-FEDER-00010

49 Reference number Acores-09-4842-FEDER-000035.

50 Reference numbers ALT20-06-4842-FEDER-000117 and ALT20-06-4842-FEDER-000157.

51 Reference number M1420-08-4842-FEDER-000001.

52 See: https://enil.eu/wp-content/uploads/2020/07/Complaint_by_Independent_Living_Austria_ENIL.pdf.

2. A new residential facility, accommodating 3 groups of 7, with a total capacity of 21 persons with disabilities, located in the same building as a sheltered workshop;
3. A new residential facility, with places for 20 persons with disabilities;
4. A new residential facility, with places for 12 persons with disabilities, mostly persons with autism;
5. – 6. Two new residential facilities, with places for 16 persons with motor and cognitive impairments each.

In addition, two sheltered workshops were built – one with 24 places and one with 32 places – both aimed at people with motor and cognitive impairments. The latter workshop is located in the same building where persons with disabilities live.

ENIL and ILA have argued that the projects co-financed by EAFRD reinforced the segregation, isolation and discrimination of persons with disabilities in Upper Austria. Instead of supporting inclusive living arrangements, by improving access to housing that is open to the general population, and expanding the provision of mobile support and personal assistance services for persons with disabilities, the State of Upper Austria invested additional substantial resources into expanding special facilities, where only persons with disabilities can live. The same applies to sheltered workshops, which are segregating, exclude persons with disabilities from the general labour market and keep individuals and families in poverty.

That there is a need for more community-based services in Upper Austria is evidenced by official statistics, according to which the majority of persons with disabilities already live in institutions or are occupied in sheltered workshops. Based on data from 2018, a total of 4,635 persons with disabilities in Upper Austria (70%) lived in smaller or larger living facilities. Compared to this, community-based services are much less available. A total of 1,746 persons received mobile support/help and only 215 benefited from personal assistance. With regard to sheltered workshops (referred to as the “ability oriented activity”), a total of 5,751 persons with disabilities attended such facilities in 2018. In contrast, a total of 846 persons (15%) were in groups for integrated occupation, within regular employment schemes.

The system of sheltered workshops has been criticised as discriminatory by experts and Austria’s equality body, due to discrimination of persons with disabilities in such facilities. Reasons cited include: no independent social security; not being subject to employment protection laws; no legal representation; not being eligible for retirement; no wages received for the work performed; transfers from sheltered workshops into the regular labour market scarcely occur. It is considered particularly problematic if the housing and sheltered workshop are organised by the same service provider or in the same building.⁵³

53 Austrian Ombudsman Board, 2018. Written Contribution, page. 29. Available from: https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=INT%2fCRPD%2fIFR%2fAUT%2f32189&Lang=en

3.2. Failure to invest into community-based services, such as personal assistance, and accessible housing

Summary of the issue: Personal assistance is recognised as a key tool for independent living, yet not many Member States use ESI Funds to facilitate access to personal assistance. Those that do are not making it available to persons with disabilities leaving institutions. In Member States where personal assistance is funded through the European Social Fund (such as Croatia and Portugal), this service is aimed at people living in the community and is limited in coverage and scope (i.e. the maximum number of hours a person can have assistance for). ESI funds have also not been used to significantly increase availability of housing options for persons with disabilities, such as social housing, or accessible and affordable houses and apartments in the community. Instead, many persons with disabilities have been forced to choose between a large institution and a group home, or another segregated setting.

In **Austria**, the fact that persons with disabilities in institutions cannot use personal assistance to move out was described to ENIL as “a major barrier to deinstitutionalisation”. Notably, ESI Funds are not used to fund personal assistance in Austria, while they are being used to build and renovate institutions for persons with disabilities.

In **Croatia**, the European Social Fund (ESF) was used to expand personal assistance to include a larger number of persons with disabilities, including people with intellectual disabilities and people with psychosocial disabilities. From 500 users in 2016, thanks to the ESF-funded project⁵⁴, the number of personal assistants grew to 1,550 users in 2018. In addition, as part of the same funding, ESF has provided for employment of 84 sign language interpreters and 35 seeing guides used by deaf persons, deaf and blind and blind/visually impaired persons. The Managing Authority is providing funds to a large number of NGOs managing personal assistance services through three-year programs. However, the ESF-funded personal assistance is not available to those leaving institutions, so that they could move into regular apartments in the community and be supported by personal assistants.

Hungary: EU-funded “supported housing” facilities found to be in violation of Article 19 CRPD by the United Nations

In January 2017, the Hungarian Government published a call for proposals, entitled “Human Resources Development Operational Programme (EFOP) 2.2.2 – 17. Conversion of institutional supply to community-based services – replacing institutional places”.

⁵⁴ See: <http://www.esf.hr/natjecaji/socijalno-ukljucivanje/razvoj-usluge-osobne-asistencije-za-osobe-s-invaliditetom-faza-ii-2/>

In August 2017, it was announced that 29 large institutions for persons with disabilities are to be awarded a total of 22.7 billion HUF (approx. 73 million EUR) to carry out projects affecting nearly 2,600 people. The 29 approved projects involve the construction of 181 new institutions (accommodating between 8 and 12 individuals in single or double bedrooms) and the renovation of 8 already existing buildings. Implementation of this process has advanced significantly since 2017.

The EU funded settings – referred to as “supported housing” – have been criticised widely for lack of compliance with the CRPD. For example, the Academic Network of European Disability Experts (ANED) report noted in 2019 that the current legislation on supported housing is not clearly distinguished from other residential institutions; thus, the same rules apply to supported housing as to large institutions. It also found that the current financing system is not based on individual needs” and that “institutional culture is still stronger in the supported housing regulatory model than the community-based service character”⁵⁵.

Another recent study⁵⁶ highlighted the following institutional characteristics of Hungary’s group homes: the study compared being placed in supported housing to a system of referral to an institution, rather than a “free home choice”. It noted the service user had “no influence on the services and supports he/she receives in supported housing and little to no choice about their “supportive network”. It concluded that “the current system is based on an essentially old institutional system”.

These findings were confirmed in the United Nations report, made publicly available in March 2020, which followed a 3-year inquiry into the alleged grave and systematic violations of Article 12 (equal recognition before the law), Article 19 (living independently and being included in the community) and Article 5 (equality and non-discrimination) of the CRPD. The report, carried out under Article 6 of the Optional Protocol to the CRPD, found that EU funded “supported housing” facilities helped maintain institutionalisation of persons with disabilities in Hungary:

“A significant amount of resources, including from the European Structural and Investment Funds, has continued to be invested in expanding the institutionalization of persons with disabilities, including through a strategy of moving persons with disabilities from large-to small-scale group homes, preventing their inclusion in society.”⁵⁷

55 Gyulavári, T et al, 2019. *Living independently and being included in the community. Country report: Hungary*, ANED 2018 – 2019, pages 2 and 16. Available from: <https://www.disability-europe.net/country/hungary>

56 Referred to on page 29 of the ANED report on Hungary.

57 UN Inquiry on Hungary, paragraph 1b.

The report highlighted a number of features of “supported housing” which made them institutions. It said that persons with disabilities, the majority of whom remain under guardianship, “continue experiencing disempowerment, and limitations in their autonomy to make choices of their life” and “remain dependent from large institutions, including in access to food and health care”. It further went on to describe in detail other institutional features of the EU funded facilities: the fact that they remain under the control and management of directors and staff of institutions, the lack of self-determination and restrictions to private life of residents, and the lack of individualized support”.⁵⁸

The UN found both grave and systematic violations of Articles 12, 19 and 5 in Hungary, and urged its Government to:



“Reorient the investment of public funds – including the way in which funding from the European structural and investment funds is allocated – from institutions to support in the community by **accelerating the development of a full range of in-home and other community services offering support in daily life, including personal assistance, and other forms of supported decision-making.**”⁵⁹

3.3. Replacing large institutions for children with disabilities with smaller institutions

Summary of the issue: Whereas the closure of institutions for children has progressed faster, many children with disabilities were moved into smaller residential facilities (referred to, among other, as family-like homes, family homes and small group homes), rather than being returned to their biological families or provided with other forms of family-based care. According to information available to ENIL, in 2014 – 2020, this has been the case for Austria, Bulgaria, Estonia, Lithuania and Romania.

In **Bulgaria**, for example, Disability Rights International (DRI) published a major report⁶⁰ in December 2019 based on visits to 24 group homes for children with disabilities across the country. The investigation revealed that the availability of ESI Funds for group homes was “one of the major motivating forces” which

⁵⁸ *Ibid*, paragraphs 66 – 69.

⁵⁹ *Ibid*, paragraph 112e.

⁶⁰ Disability Rights International, 2019. A Dead End for Children – Bulgaria’s Group Homes. Available from: <https://www.driadvocacy.org/wp-content/uploads/Bulgaria-final-web.pdf>

encouraged municipal authorities to build the new facilities, whether such services were needed or not. Considering that the bigger the facilities, the more funding was available, this acted as an incentive to build institutions for as many children as possible; typically with 14 beds, but some municipalities also clustered several group homes together. The report went on to state that municipalities competed with one another, in order to use as much EU funding as possible while it was available. In addition, “since some funding came from an EU project to assist less developed areas, remote locations had an incentive to build group homes and worry later about how to bring in children from other parts of the country.”⁶¹

DRI found that from 2010 to 2015, the EU invested more than 100 million EUR in the reform of the child protection system in Bulgaria, with an additional 160 million invested into deinstitutionalisation reforms since 2016. Numerous human rights violations were found in the group homes visited by DRI, which continue to be built and accept those children with disabilities for whom no family-based alternatives are available.

In **Austria**, ILA collected information about a new living unit for people with complex support needs funded with ESI Funds, placed in a large residential institution accommodating about 200 children and adults with disabilities.

Bulgaria: Challenging the use of ESI Funds in the General Court in Luxembourg

In September 2019, ENIL, the Centre for Independent Living Sofia (CIL Sofia) and the Validity Foundation initiated Court proceedings against the European Commission at the EU General Court in Luxembourg for failing to prevent ERDF from being invested in the building of group homes for adults with disabilities. They filed an application for annulment under Article 263 of TFEU, and were supported pro bono by the law firm Covington & Burling LLP. Expert opinions, in support of the application, were submitted by experts on the CRPD and EU law, Prof. Gerard Quinn (see Foreword) and Prof. Grainne de Burca (NYU School of Law).

Case T-613/19 was sparked by the Call for Proposals BG16RFOP001-5.002 (“Support for deinstitutionalisation of services for adults and people with disabilities”), co-financed by ERDF in the amount of nearly 18 million Euros. This funding was foreseen for the building, renovation, furnishing and equipment of 6 day-care centres and 68 group homes for older people and persons with disabilities, including persons with psychosocial disabilities, intellectual disabilities and persons with dementia. It was allocated to 29 municipalities, with each set to build a number of new facilities with a capacity of 15 people per group home. Altogether, this call affects 1,020 individuals.

Most of the municipalities which were awarded funding plan to build multiple group homes, with the highest number being 9 facilities in one municipality. Some of these are located in small towns.

61 *Ibid*, page 14.

For example, one of the municipalities is planning to build 7 new group homes to accommodate women from a 100 place local institution. The town where these will be located has only 8,000 inhabitants.

The Managing Authority refused to suspend and/or substantially revise the call, and the European Commission refused to use their powers to intervene. It is for this reason that the three organisations decided to take the European Commission to Court.

In September 2020, the General Court dismissed the application as inadmissible. It found that the Commission's decisions (not to suspend payments) had no legal effect on ENIL, CIL Sofia and the Validity Foundation; that the applicants represented in the case (i.e. persons with disabilities in institutions) cannot be considered 'beneficiaries' of the financial assistance, for which reason the Commission's actions do not affect them directly and individually; and that "the defence of the general and collective interests of a category of persons is not sufficient to establish the admissibility of an action for annulment brought by an association or organisation and in the absence of special circumstance". The Court did not look into the substance of the case, i.e. whether the group homes built with ESI Funds breach EU law.

3.4. Lack of progress with deinstitutionalisation

Summary of the issue: Despite having deinstitutionalisation as one of the priority areas, all the Member States concerned failed to make significant progress with closing down institutions for persons with disabilities. More progress was noted with regard to children with disabilities, but many children were moved into small group homes, rather than (re)integrated in families. Among the issues identified was the lack of vision by the governments on independent living and the lack of ownership of the process, which may feel as if imposed by the EU. In several Member States with a large number of persons with disabilities in institutions, including France, Belgium, Germany and Spain, deinstitutionalisation has not been a priority for ESI Funds at all.

In **Croatia**, for example, the process of deinstitutionalisation has slowed down significantly and according to information obtained by ENIL, 85% of the ESI Funds allocated for deinstitutionalisation have not been used for this purpose and have been redirected into other priority areas. The transformation of social care homes has, in some cases, resulted in services that replicate institutional culture and has failed to facilitate access to independent living. Foster care for adults has been expanded as an alternative to institutions, despite the service not being in line with Article 19 CRPD.

In **Slovakia**, due to delays and complicated public procurement, only 16 transformation projects have been selected for ERDF support (10 institutions for persons with disabilities and 6 children's homes). The call has been closed to further applicants, because it was not realistic to finalise it before the end of 2023. A second ERDF call aimed at creating new community-based services, mostly targeting older people, was more successful, with 67 projects approved.

After significant delays, it is positive that the National Deinstitutionalisation Project⁶² in Slovakia – co-funded through ESF and ERDF – started its activities at the end of 2018. There are 49 institutions involved in the training, consultation and supervision. After 23 months, the plan is for each institution to have a transformation plan in place, which will be a condition for using ERDF. The expert team will use the WHO QualityRights Toolkit⁶³ to monitor the readiness of the institutions for transformation, and has taken part in the training of monitoring teams. NGOs are involved in the National Project in an advisory capacity.

In another positive example, in the **Czech Republic**, ESI Funds (ESF and ERDF) are being used for psychiatric reform, with the aim of substantially reducing the number of long-term beds in psychiatric hospitals and creating a range of community-based services to support people with psychosocial disabilities living in the community (including prevention services and new services, such as those for children). These measures are accompanied by anti-stigma campaigns and awareness raising, data collection and analysis. The project is led by the Ministry of Health, and is implemented in cooperation with other relevant ministries between 2017 – 2022⁶⁴.

3.5. Building and renovation of large institutions, in some cases under the pretext of improving “energy efficiency”

Summary of the issue: Large institutions for persons with disabilities – accommodating children, adults and older people – continue to benefit from ESI Funds’ investments. In some Member States, funds from ERDF have also been used to renovate institutions. While such investments have been difficult to monitor, ENIL is concerned that improving “energy efficiency” of institutions has been wide-spread during 2014 – 2020 and that such projects have typically been multi-million Euro investments.

In **Poland**, for example, ENIL and Validity Foundation submitted a complaint⁶⁵ against the Łódź Voivodeship in August 2020, for using ERDF to build, renovate, extend or modernise institutions for persons with disabilities, including some with up to 80 or 90 residents. Some of the institutions have already been built or renovated, while others are yet to be built.

62 See: <https://npdi.gov.sk>

63 WHO QualityRights Toolkit, available from: https://www.who.int/mental_health/publications/QualityRights_toolkit/en/

64 For more information, see: http://www.esifundsforhealth.eu/sites/default/files/2018-08/Dita%20Protopopova%20CZ%20Ministry%20of%20Health_1.pdf and <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6357523/f>

65 See: https://enil.eu/wp-content/uploads/2020/08/Complaint_Poland.pdf

The eight projects challenged in this complaint have been funded under four different calls for proposals, and are all under the management of Łódź Voivodeship. They include: the construction of an institution for over 90 persons in a 4-storey building, next to an already existing 140-person institution in the town of Łódź; the extension and conversion of an 80-person institution in Drzewica; the building of an institution for 60 people.

In **Estonia**, the 2019 financial report of the agency responsible for adult social care services claims that “building [institutions] in a sustainable way” is a priority in itself. All of the new institutions for persons with disabilities are ‘nearly-zero-energy-buildings’, which means that maintaining them is very cost-effective.

3.6. Lack of involvement of organisations of persons with disabilities (DPOs)

Summary of the issue: Despite the obligation to involve civil society organisations in all the stages of ESI Funds use, Member States still fail to involve persons with disabilities and their representative organisations in decisions about the use of ESI Funds. This is especially true during the implementation, monitoring and evaluation stages. Those that are more open to DPO participation, do not provide funding to all organisations to ensure they have the necessary capacity to be a part of this process. The COVID-19 pandemic has also had an impact on the DPO involvement in the planning of the 2021 – 2027 programming period. This was reported to ENIL by organisations in Croatia and Bulgaria.

In **Austria**, the partnership principle is reduced to membership of one representative of the Austrian Disability Council in the ESI Funds advisory groups, which meet 2 or 3 times a year. This makes it impossible for persons with disabilities and DPOs – which cannot be represented by a single organisation – to access information and have control over how ESI funds are used.

In **Belgium**, the Managing Authority reportedly claims that they are not obliged to consult with NGOs in the planning of the post 2020 programming period.

In **Hungary**, the CRPD Committee expressed concern that “some civil society organizations have experienced reprisals for expressing critical views about governmental disability-related policies, such as restrictions in their independent monitoring of social services for persons with disabilities, including institutions.” It also found that organisations of persons with disabilities receiving public funds “are less inclined to express openly disseminating opinions about government policies”, while grassroots organisations are more critical, but also have limited capacity to influence decision-making.⁶⁶

A positive experience was reported to ENIL from **Slovakia**, where NGOs are being consulted about the use of ESI Funds for persons with disabilities through an established mechanism. However, their capacity to be fully involved in the process was raised as a problem.

66 UN Inquiry on Hungary, paragraph 91.

Romania: Plans for ERDF funded “sheltered housing” units to replace large institutions for persons with disabilities

In November 2019, ENIL submitted a complaint to the European Commission against the Ministry of Public Works, Development and Administration in Romania, because of the ERDF-funded call for tenders P.O.R./8/8.1/8.3/B/1. The call foresees the opening of sheltered housing ('locuinte protejate', literally translated as 'protected housing') and day care centres for adults with disabilities, by refurbishing existing infrastructure and building new facilities. It was open to county-level authorities alone or in partnership with NGOs, and targeted large residential institutions for persons with disabilities with more than 120 residents. The call was closed on 20 April 2018, with the total funding contracted amounting to EUR 16 million. This allows for the opening of 65 sheltered housing units and 21 day care centres.

ENIL was able to collect documentation for 18 successful tenders from 7 counties, comprising 57 sheltered housing units and 18 day care centres, designed to accommodate 460 and 533 beneficiaries respectively. Information regarding the remaining 8 sheltered housing units and 3 day care centres is not publicly available. The implementation period for all the projects has already started and is expected to end by 2022 at the latest.

The sheltered housing units will accommodate between 6 – 10 persons each, and based on the available documentation for the 18 successful tenders, they will be organised as follows: 14 units with 10 persons each; 6 units with 9 persons each; 22 units with 8 persons; and 15 units with 6 persons each.

Importantly, all but two of the nine awarded projects will build the sheltered housing units on the same perimeter, thus resulting in:

- 6 complexes with 30 residents or more;
- 8 complexes with 20 residents or more;
- 5 complexes with 16 residents or more; and
- 1 complex with 8 residents.

They will be located in small villages or in small towns, in some of the most deprived areas of the country and the EU. Residents of these facilities – which are considered to be places where persons with disabilities are deprived of their liberty – will be subject to block treatment, with a high likelihood of human rights abuses taking place. They will be forced to spend their days in day care centres and meaningless activity, without any opportunity to live independently and to be included in community.

CHAPTER IV

The way forward

4.1. New legislative framework for 2021 – 2027

On 29 and 30 May 2018, the European Commission published its proposals for the European Social Fund+ (ESF+), the European Regional Development

Fund (ERDF) and the Cohesion Fund, for the new programming period 2021 – 2027⁶⁷. Two months later, the Member States agreed on the new Multiannual Financial Framework of 1,074.3 billion Euros and an additional 750 billion Euros under Next Generation EU, to help with the COVID-19 response and recovery.

Although the new legal framework for 2021 – 2027 is yet to be finalised, it is positive that the draft regulations refer to the need “to respect the obligations of the UN Convention on the Rights of Persons with Disabilities”⁶⁸. Instead of ex ante conditionalities, the new regulations introduce “enabling conditions”, which should be monitored and applied by the Member States throughout the programming period. According to the Commission’s proposal, Member States would not receive funds until the relevant enabling condition is fulfilled, thus ensuring that all investments “are in line with the EU policy framework”.

There are two relevant “horizontal enabling conditions” in the draft Common Provisions Regulation: effective application and implementation of the EU Charter of Fundamental Rights, and implementation and application of the CRPD, in accordance with Council Decision 2010/48/EC. The main “thematic enabling condition” related to living independently is the existence of the national strategic policy framework for social inclusion and poverty reduction, which includes measures for the shift from institutional to community-based care.

Both “enabling conditions” have the potential to encourage investment in community-based services and to prevent the building and renovation of institutions, but only if they are implemented by the Member States, and are monitored by both Member States and the Commission.

4.2. COVID-19 response and recovery

The significant amount of additional funding made available to the Member States to respond to the challenges brought by the COVID-19 pandemic, particularly REACT-EU and the Recovery and Resilience Facility, is of key relevance to persons with disabilities and their representative organisations. As highlighted

⁶⁷ See: https://ec.europa.eu/commission/future-europe/eu-budget-future_en and <https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=COM%3A2018%3A375%3AFIN>

⁶⁸ European Commission, Proposal for a Regulation of the European Parliament and of the Council laying down common provisions on the European Regional Development Fund, the European Social Fund Plus, the Cohesion Fund, and the European Maritime and Fisheries Fund and financial rules for those and for the Asylum and Migration Fund, the Internal Security Fund and the Border Management and Visa Instrument, COM(2018) 375 final, 29 May 2018, recital 5, CPR. Available from: https://ec.europa.eu/commission/sites/beta-political/files/budget-may2018-common-provisions_en.pdf.

by the COVID-19 Disability Rights Monitor⁶⁹, the pandemic has had a devastating impact on people in institutional care settings. It has proven what was already known – that institutions pose a major risk to the lives and health of children, adults and older persons with disabilities, and should be closed as a matter of urgency. Notably, vital community-based services, such as personal assistance, family-based support services and rehabilitation, have also been affected.

The additional funding provides Member States with an opportunity to accelerate deinstitutionalisation reforms (in the form of “emergency deinstitutionalisation”) and to invest in the community-based services and infrastructure during and after the pandemic. However, there is also a risk that REACT-EU and the Recovery and Resilience Facility will be used to reinforce institutional care provision – by additional investments into human resources, equipment and institutional infrastructure. There are concerns, for example, that EU funds could be used provide conditions for social distancing in institutions, to build new facilities for isolation of COVID-19 positive residents or to further medicalise the provision of care in these settings. With monitoring of institutions by the national human rights institutions and NGOs severely restricted during the pandemic, there is a real danger that such investments may go undetected.

4.3. Conclusion and recommendations

The new programming period provides the European Union with another opportunity to get things right; to move closer to the goal of independent living for all children, adults and older with disabilities. The COVID-19 pandemic has brought to fore the dangers of institutional care settings and the need to make community-based options, such as personal assistance and accessible housing in the community, available as a matter of priority. At this moment, enabling people to leave institutions as soon as possible could save thousands of lives.

This study has brought together legal and policy arguments, and evidence, that should make investing ESI Funds in institutions of any size impossible. Yet, as highlighted in the lessons learned, there are ongoing projects and plans that will result in new institutions all over the EU.

Therefore, the following steps should be taken by the Member States and the European Commission to move forward with the goal of independent living for all and to prevent investments into institutional care services:

- The use of ESI Funds should be **strictly limited to projects that fully comply with the UN Convention on the Rights of Persons with Disabilities**, in particular Article 19, as explained in the General Comment No. 5, but also other articles. The European Commission should **suspend investments or otherwise sanction** Member States which continue using ESI Funds to build or renovate institutions of any kind. It should also seek to prevent projects

69 COVID-19 Disability Rights Monitor Coordinating Group, 2020. *Disability rights during the pandemic – A global report on findings of the COVID-19 Disability Rights Monitor*, pages 22 – 27.

aiming to build new institutions and other segregating services (such as sheltered workshops) for persons with disabilities from going ahead.

- The European Commission should **withdraw, as a matter of priority, the internal Legal Opinion of June 2018**, which allows for investments in institutions. Any **future guidance by the Commission’s legal service should be in line with the CRPD and the jurisprudence of the CRPD Committee**, and respectful of decisions by the European Ombudsman concerning the use of ESI Funds.
- Member States should **closely coordinate the use of the European Social Fund (ESF) and the European Regional Development Fund (ERDF), in order to develop a range of services that support living independently and being included in the community**. This would help facilitate **access of persons with disabilities to the twelve pillars of independent living**: adequate provision of personal assistance, availability of accessible and adapted housing, adequate provision of technical aids and equipment, availability of inclusive education and training, full access to the environment, an adequate income, appropriate and accessible health and social care provisions, a fully-accessible transport system, and appropriate and accessible information.
- Member States should **use React-EU and the Recovery and Resilience Facility to support “emergency deinstitutionalisation”**, by supporting the development of community-based services that would allow as many people as possible to leave institutions in the shortest amount of time.
- Member States should ensure **close consultations with and involvement of persons with disabilities**, through their representative organisations, in all stages of ESI Funds use. To increase the capacity of user-led organisations, and organisations which promote independent living, to participate in this process, **Member States should allocate adequate funding for their work**.
- The European Commission should **closely monitor** implementation of ESI Funds within the current programming, and plans for 2021 – 2027, in order to prevent projects that fail to comply with the CRPD from going ahead. Both the **European Commission and the Member States should make use of opportunities for technical assistance and capacity building** by the CRPD Committee (under Article 37 CRPD), and the expertise on independent living and deinstitutionalisation by persons with disabilities and their representative organisations, at the local, national and EU level.

ANNEX I: Definitions

Independent Living

The right to living independently and being included in the community is set out in Article 19 of the UN Convention on the Rights of Persons with Disabilities (CRPD) and further defined in the General Comment No 5.

The General Comment 5 on living independently and being included in the community defines 'Independent Living' as follows:

“Independent living/living independently means that individuals with disabilities are provided with all necessary means to enable them to exercise choice and control over their lives and make all decisions concerning their lives. Personal autonomy and self-determination are fundamental to independent living, including access to transport, information, communication and personal assistance, place of residence, daily routine, habits, decent employment, personal relationships, clothing, nutrition, hygiene and health care, religious activities, cultural activities and sexual and reproductive rights. These activities are linked to the development of a person's identity and personality: where we live and with whom, what we eat, whether we like to sleep in or go to bed late at night, be inside or outdoors, have a tablecloth and candles on the table, have pets or listen to music. Such actions and decisions constitute who we are. Independent living is an essential part of the individual's autonomy and freedom and does not necessarily mean living alone. It should also not be interpreted solely as the ability to carry out daily activities by oneself. Rather, it should be regarded as the freedom to choose and control, in line with the respect for inherent dignity and individual autonomy as enshrined in article 3 (a) of the Convention. Independence as a form of personal autonomy means that the person with disability is not deprived of the opportunity of choice and control regarding personal lifestyle and daily activities.”⁷⁰

Community living

The term 'community living' is used to refer to the right of persons with disabilities to live in their local communities and receive the support they need to participate in every-day life. This includes, for example, living in their own homes or with their families, attending the same schools or working in the same places as their non-disabled peers, and taking part in community activities they choose.

⁷⁰ General Comment 5, para 16(a).

Group homes/Institutional care

The term ‘group homes’ refers to buildings, houses or apartments where persons with disabilities live together. Some countries will use other terms, such as protected homes, sheltered homes, organised housing or even supported or assisted living.

If group homes have one or more of the following ‘institutional care’ characteristics, they can be considered as institutional in character and not compliant with Article 19 CRPD⁷¹:

- 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;
- a disproportion in the number of persons with disabilities living in the same environment.

General Comment 5 goes on to state that institutional settings with these characteristics “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”.

Family-like/Family-type homes for children

Group homes for children are often referred to as ‘family-type’ or ‘family-like’ homes or centres. What defines ‘family-like’ and ‘family-type homes’ is that groups of children are placed together, with carers (and other professionals) working in shifts taking care of the children. General Comment 5 on living independently and being included in the community states that, with regard to children, anything other than a family is considered an institution, as there can be no substitute for growing up with a family.⁷²

Deinstitutionalisation

The European Network on Independent Living defines ‘deinstitutionalisation’ as:

⁷¹ *Ibid*, para 16(c).

⁷² *Ibid*, para 16(c).

“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.”

The Toolkit on the Use of European Union Funds for the Transition from Institutional to Community-based Care⁷³ describes ‘deinstitutionalisation’ as a process which includes:

- the development of high quality, individualised services based in the community, including those aimed at preventing institutionalisation, and the transfer of resources from long-stay residential institutions to the new services in order to ensure long-term sustainability;
- the planned closure of long-stay residential institutions where children, disabled people (including people with psychosocial disabilities), homeless people and older people live, segregated from society, with inadequate standards of care and support, and where enjoyment of their human rights is often denied;
- making mainstream services such as education and training, employment, housing, health and transport fully accessible and available to all children and adults with support needs.

Emergency deinstitutionalisation

The term ‘emergency deinstitutionalisation’ refers to protecting peoples’ basic rights to live in the community, getting them the support required to leave the institution in the short term, and subsequently providing any additional support and access to mainstream society, in line with the UN Convention on the Rights of Persons with Disabilities. The aim is to achieve the transition as fast as possible, during and in the aftermath of the COVID-19 pandemic, while preventing against homelessness, absence of formal support services and over-reliance on informal care.

⁷³ European Expert Group on the Transition from Institutional to Community-based care, *Toolkit on the Use of European Union Funds for the Transition from Institutional to Community-based care*, 2014.

ANNEX II: Sources and further reading

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