



Shadow report on the implementation of the UN Convention on the Rights of Persons with Disabilities in the European Union

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About the European Network on Independent Living

The European Network on Independent Living (ENIL) is a Europe-wide network of disabled people, with members throughout Europe. ENIL is a forum for all disabled people, Independent Living organizations 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.

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List of abbreviations

CEE	Central and Eastern Europe
CRPD	Convention on the Rights of Persons with Disabilities
CRPD Committee	Committee on the Rights of Persons with Disabilities
DPO	Disabled People's Organisation
EAFRD	European Agricultural Fund for Rural Development
EC	European Commission
EEA	European Economic Area
EIB	European Investment Bank
ENIL	European Network on Independent Living
ERDF	European Regional and Development Fund
ESI Funds	European Structural and Investment Funds
EU	European Union
IMF	International Monetary Fund
LOIPR	List of Issues Prior to Reporting
NGO	Non-governmental Organisation
UN	United Nations

Introduction

Scope and purpose

The purpose of this report is to analyse how the European Union (EU) implemented the UN Convention on the Rights of Persons with Disabilities (CRPD) between 2015 and 2022. Drawing on existing empirical evidence, the report raises serious concerns about the implementation of the CRPD by the EU. While Article 19 on the right to live independently and being included in the community is the primary focus, the report illuminates how the denial of the right to live independently in the community impacts other fundamental human rights including Article 10, Right to life and Article 15, Freedom from torture or cruel, inhuman, or degrading treatment or punishment.

In 2014, the European Network on Independent Living submitted its first shadow report on the implementation of Article 19 of the UN Convention on the Rights of Persons with Disabilities in the European Union¹. Many of the key concerns expressed in that report have not been addressed in the seven years since the first report. In fact, this report gathers evidence showing that many of the concerns are exacerbated by the continued investment of European funds to reinforce institutional segregation of disabled people² throughout Europe.

In 2020, a report on institutionalisation across 27 Member States estimated that there are at least 1, 438, 696 European citizens confined to institutions and these numbers have not substantially changed in the past 10 years³. Furthermore, there are more than 302,979 children in residential care in the EU countries⁴. This failure to close institutions had devastating consequences when the COVID-19 pandemic spread across the EU. The pandemic exposed the failure to provide the most basic human rights protections within institutions large and small. Deprivation of liberty intensified during the COVID-19 pandemic, with reports of increased physical and chemical restraints⁵. Disabled people in institutions accounted for the majority of COVID-19 related deaths in many EU Member States⁶.

¹ ENIL and ECCL (2014). Realising the Right to Independent Living: Is the European Union Competent to Meet the Challenges? Available at <http://www.enil.eu/wp-content/uploads/2012/06/Shadow-Report-11-04-2014-final-WEB-1-1.pdf>

² We use the term 'disabled people' in this report, in line with the social model of disability, to acknowledge the disabling social, economic and attitudinal barriers.

³ Šiška, J., & Beadle-Brown, J. (2020). Report on the Transition from Institutional Care to Community-Based Services in 27 EU Member States. European Expert Group on Transition from Institutional to Community-Based Care.

⁴ Eurochild (2021) Children in alternative care: Comparable statistics to monitor progress on deinstitutionalisation across the European Union. Available at: https://eurochild.org/uploads/2021/12/Children-in-alternative-care_Comparable-statistics-to-monitor-progress-on-DI-across-the-EU.pdf

⁵ Stall, N. M., Zipursky, J. S., Rangrej, J., Jones, A., Costa, A. P., Hillmer, M. P., & Brown, K. (2021). Assessment of psychotropic drug prescribing among nursing home residents in Ontario, Canada, during the COVID-19 pandemic. *JAMA Internal Medicine*, 181(6), 861-863

⁶ Comas-Herrera, A. et al (2021). Mortality associated with COVID-19 in care homes: international evidence. *International Long-Term Care International*.

Considering the deterioration of disability rights across Europe, ENIL's main concerns are:

- **Continuing investment** of EU funds (from the ESI Funds and EIB) in institutions for disabled children and adults, including group homes, and in nursing homes, many of which practice torture, including the use of cage beds and straightjackets, and deny basic healthcare;
- **Lack of meaningful consultation** and involvement of disabled people and their representative organisations in EU law and policy;
- **Inadequate non-discrimination measures** due to failure to adopt a horizontal directive for equal treatment outside the field of employment;
- **Deprivation of legal capacity and limited access to justice**;
- **Inadequate monitoring and complaints mechanisms** in EU policies impacting disabled people;
- **Lack of access to supports and services** including personal assistance, inclusive education, and employment.

EU competencies and the UN CRPD

Pursuant to Article 216 of the Treaty on the Functioning of the European Union, 'the agreement is legally binding upon the EU institutions and the Member States. Responsibility to implement the Convention is shared between the EU and the Member States, covering the extent of their respective competences'⁷. All EU Member States have ratified the Convention as of March 2018.⁸ While EU confirmation represents a significant human rights milestone, it also presents several challenges in defining EU competencies. More information about the EU competences in the areas covered by the report can be found in **Appendix 2**.

EU implementation of the CRPD

Twelve years have passed since the CRPD became the first United Nations Treaty to be confirmed by the EU. The European Commission submitted the first implementation report to the UN Committee on the Rights of Persons with Disabilities in June 2014, covering the period from January 2011 to December 2013.⁹ In September 2015, the

⁷ European Parliament (2016). EU Implementation of the UN Convention on the Rights of Persons with Disabilities (CRPD), p. 9. Available at

[https://www.europarl.europa.eu/RegData/etudes/IDAN/2016/536347/EPRS_IDA\(2016\)536347_EN.pdf](https://www.europarl.europa.eu/RegData/etudes/IDAN/2016/536347/EPRS_IDA(2016)536347_EN.pdf)

⁸ The European Union currently has 27 Member States. The United Kingdom was a member of the European Union until 31 January 2020.

⁹ Initial report of the European Union, 5 June 2014. Available at:

https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fEU%2f1&Lang=en

CRPD Committee finalised its first review of the EU by issuing Concluding Observations.¹⁰ They included the following recommendation:

‘that the European Union develop an approach to guide and foster deinstitutionalization and to strengthen the monitoring of the use of the European Structural and Investment Funds so as to ensure that they are used strictly for the development of support services for persons with disabilities in local communities and not for the redevelopment or expansion of institutions. The Committee also recommends that the European Union suspend, withdraw and recover payments if the obligation to respect fundamental rights is breached’¹¹.

Despite formal complains made by ENIL about the use of European funding in breach of EU Law¹², and contrary to the CRPD Committee’s recommendations, the EU has continued to support investments in large and small institutions, justified as a temporary measure or as a measure suitable for ‘persons requiring constant care and medical supervision’¹³. The complaints, submitted by ENIL and its members, have been consistently rejected on this ground. The flawed complaint procedure, based only on the examination of documents submitted by the authorities, has also not allowed for an objective assessment of the situation. It was only after a CRPD Committee’s inquiry (under the Optional Protocol to the CRPD) criticised the institutional character of some EU-funded services that the EU intervened, albeit in one case.

The creation of group homes and other segregating arrangements as an ‘alternative’ to large institutions has been a persistent problem of the EU-funded deinstitutionalisation process, hindering the implementation of Article 19. According to General Comment No.5, ‘[a]rticle 19 is not properly implemented if housing is only provided in specifically designed areas and arranged in a way that persons with disabilities have to live in the same building, complex or neighbourhood’¹⁴.

In addition, group homes cannot be called independent living arrangements:

‘if they have other defining elements of institutions or institutionalisation’, such as, ‘obligatory sharing of assistants with others and no or limited influence over whom one has to accept assistance from; isolation and segregation from independent life within the community; lack of control over day-to-day decisions;

¹⁰ Committee on the Rights of Persons with Disabilities (2015). Concluding observations on the initial report of the European Union CRPD/C/EU/CO/1. Available at: https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fEU%2fCO%2f1&Lang=en

¹¹ Ibid.

¹² European Network on Independent Living (2020). Complaint – Infringement of EU law. Available at https://enil.eu/wp-content/uploads/2020/12/Romania_Complaint_ESIF_131219_FIN.pdf.

¹³ European Commission Legal service, Ref. Ares(2018)3471732-29/06/2018.

¹⁴ Committee on the Rights of Persons with Disabilities (2017). General comment No. 5 (2017) on living independently and being included in the community. Available at: http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/5&Lang=en, para. 34. [hereinafter General Comment No5].

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’.

The General Comment also emphasises that ‘[l]arge or small group homes are especially dangerous for children, for whom there is no substitute for the need to grow up with a family’, noting that ‘family-like’ institutions are still institutions¹⁵. Similarly, the Special Rapporteur on the rights of persons with disabilities notes that ‘[a]ny placement of children in a residential setting outside a family must be considered placement in an institution’¹⁶. In addition, group homes, small and large, have been found to have ‘detrimental effects on the healthy development of children, regardless of age’¹⁷.

Proposed questions for the List of Issues Prior to Reporting

1. EU investments in institutions

- What measures will the EU take **to stop the continuing investment** of EU funds (from the ESI Funds and EIB) in institutions for disabled children and adults, including group homes, and in nursing homes? (Article 19)
- How will the EU ensure that EU-funded projects **do not prioritise investments in small and large institutions**, such as group homes, but are directed towards mainstream living arrangements, personal assistance, provision of accessible and affordable housing in the community, support for families, and other services in the community? (Article 19)
- What measures will the EU take to ensure that its **guidance and decisions** concerning the investment of ESI Funds in long-stay residential settings is in line with the CRPD and General Comment No. 5 and does not permit the use of EU funds in segregating settings, including group homes¹⁸? (Article 19)
- What measures is the EU taking to ensure that the **EU external action** funding only supports projects compliant with the CRPD, and does not reinforce the segregation of disabled people in large or small institutions? (Article 32)
- How will the EU ensure that **EU funding does not support institutions that practice torture** including the use of cage beds and straightjackets, and other forms of physical and chemical restraints? (Article 14, Article 15)

¹⁵ General Comment No5, para. 16c.

¹⁶ Special Rapporteur on the rights of persons with disabilities (2019). Rights of persons with disabilities. Available at: <https://undocs.org/en/A/HRC/40/54>.

¹⁷ Dozier, M., Kaufman, J., Kobak, R. O’Connor, T., Sagi-Schwartz, A., Scott, S., Shauffer, C., Smetana, J., van IJzendoorn, M., and Zeanah, C. (2014). *Consensus Statement on Group Care for Children and Adolescents: A Statement of Policy of the American Orthopsychiatric Association*, 84 *American Journal of Orthopsychiatry*. Available at: <https://www.apa.org/pubs/journals/features/ort-0000005.pdf>, p. 219.

¹⁸ Currently, EC’s legal services opinion is that investments in long-stay institutions are permitted, as long as Member States made ‘progress in general on ensuring independent living and deinstitutionalisation’ (see the section on Art.19).

2. Lack of meaningful consultation and involvement of disabled people and their representative organisations

- How will disabled people and their representative organisations be consulted and meaningfully involved by the EC/EU in the development of the **European Care Strategy and the Council Directive on Equal Treatment?** (Article 4)

3. Inadequate non-discrimination measures

- How will the EU promote the adoption of a **horizontal directive for equal treatment outside the field of employment** and what alternative legislative measures will be considered if the directive is not adopted? (Article 5)

4. Deprivation of legal capacity

- How does the EU plan to ensure that the **implementation of the 2000 Hague Convention** will not involve measures contradictory to the CRPD? (Article 12)
- How will the EU ensure that disabled people are not denied **access to justice**, due to deprivation of legal capacity? (Article 12, Article 13)
- What specific measures will the EU take to promote **supported decision-making?** (Article 12)

5. Inadequate monitoring and complaints mechanisms

- What measures will the EU take to ensure that its **complaint mechanism for breaches of EU law** involves adequate investigation, which is not limited to review of documents submitted by the government, but also includes independent assessment (for example, by national human rights institutions)? (Article 19, Article 33)

6. Lack of access to supports and services

- How will the EU ensure that EU-funded **personal assistance schemes** are consistent with the CRPD and General Comment No. 5? (Article 19)
- What measures will the EU take to ensure that the scope of the proposed **Disability Card** covers a wide range of disability benefits, including cash allocations earmarked for personal assistance, and is recognised by all Member States? (Article 18, Article 19)
- How will the EU ensure that disabled citizens are not denied the right to **healthcare?** (Article 25)
- What steps will the EU take to promote the provision of support in mainstream educational settings and in the community, allowing for **inclusive education of children with disabilities?** (Article 4)
- What measures will the EU take to ensure that EU funds are not misused to build **sheltered employment** that denies disabled people their employment rights? (Article 27)
- What measures will the EU take to ensure that the **European Solidarity Corps** programme does not support employment and volunteering in institutions?

Key concerns about the implementation of the CRPD

Article 4 (3) - General obligations

Meaningful involvement and consultation with disabled people in European Care Strategy

Article 4 (3) of the CRPD requires the close consultation and involvement of disabled people and their representative organisations in the ‘development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities’. The European Commission’s Work programme for 2022 promises ‘a European care strategy - Communication on a European care strategy, accompanied by the revision of the Barcelona targets and a proposal for a Council Recommendation on long-term care’¹⁹. It is not yet clear how disabled people and their representative organisations will be meaningfully consulted and actively involved in the development of an EU strategy that will directly impact them. Furthermore, the Commission’s Work programme for 2022 proposes a Council Directive on implementing the principle of equal treatment between persons irrespective of religion or belief, disability, age or sexual orientation²⁰.

Suggested question for the LOIPR:

- How will disabled people and their representative organisations be consulted and meaningfully involved in the development of the European Care Strategy and the Council Directive on Equal Treatment?

Article 5 - Equality and non-discrimination

Failure to adopt non-discrimination legislation

The horizontal Equal Treatment Directive, which was proposed in 2008, and would offer significant anti-discrimination rights for disabled EU citizens has been blocked in the Council of the European Union²¹. Hence, without horizontal non-discrimination legislation at EU level, disabled people are exposed to a wide range of other forms of discrimination in access to housing, goods, and services, which are not covered under

¹⁹ European Commission (2021). Commission work programme 2022. Available at https://ec.europa.eu/info/sites/default/files/com2021_645-annex_en.pdf?utm_source=POLITICO.EU&utm_campaign=a4301bea93-EMAIL_CAMPAIGN_2021_10_20_05_00&utm_medium=email&utm_term=0_10959edeb5-a4301bea93-190539799

²⁰ Ibid

²¹ Social Platform Europe (2019). Building a Social Europe for all with all. Available at <https://www.socialplatform.org/wp-content/uploads/2020/11/Social-Platform-report-on-the-European-Pillar-of-Social-Rights-Action-Plan-with-visuals-final.pdf>

European non-discrimination law²².

While it is positive that in the EU Disability Strategy for 2021-2030, the Commission calls on the Member States to enable the adoption of a horizontal directive on implementing the principle of equal treatment outside the field of employment, including disability, no specific measures are planned. It is not clear how the EC will promote the adoption of the directive and whether and what alternative legislative measures will be considered, if the directive is not adopted by the Council.

Suggested question for the LOIPR:

- What actions will the EU take to prevent discrimination on all grounds including access to goods, services, housing, healthcare, social security, and social assistance?
- How will the EU promote the adoption of a horizontal directive of equal treatment outside the field of employment and what alternative legislative measures will be considered if the directive is not adopted?

Article 7 - Children with disabilities

Placement of children with disabilities in group homes

Despite the fact that General Comment 5 explicitly states that group homes are ‘especially dangerous for children’, significant amount of the European Structural and Investment Funds (ESI Funds) has been invested in the creation of group homes for disabled children. For example, 149 ‘family-type placement centres’ were built in Bulgaria in the last decade, funded with more than 100 million EUR from the ESI Funds²³. They accommodated 70% of the disabled children leaving institutions²⁴. An assessment of the deinstitutionalisation process in the country suggested that more children could have been placed in families if greater focus had been put on the development of family and community support instead of residential settings²⁵. Furthermore, the process led to the expansion of the system of residential institutions for disabled children, with more places in residential settings than under the old system

²² Waddington, L., & Lawson, A. (2010). Disability and non-discrimination law in the European Union: An analysis of disability discrimination law within and beyond the employment field. Publications Office of the European Union, p. 60.

²³ State Agency for Child Protection (2015). Proekt “Detstvo za vsichki” za deinstitutionalizatsia na detsata s uvrezhdania (2010 r. – 2015 r.) [‘Childhood for all’ project for deinstitutionalisation of children with disabilities (2010-2015)]. Available at: <https://sacp.government.bg>

²⁴ Lumos (2015). Ending institutionalisation: an assessment of the outcomes for children and young people in Bulgaria who moved from institutions to the community. Available at: https://lumos.contentfiles.net/media/documents/document/2017/02/Bulgarian_Outcomes_Report_ENG.pdf.

²⁵ Ibid

of traditional large-scale institutions²⁶. Thus, while the EU-funded deinstitutionalisation of children in Bulgaria may have contributed to the closure of large-scale institutions, the overreliance on group homes in this process has failed to guarantee the right of disabled children to grow up in a family and to support their inclusion in the community. To this date, the European Commission has not taken any steps to sanction Bulgaria for their investments into group homes for children.

Suggested question for the LOIPR:

- How will the EU ensure that EU-funded support for disabled children does not prioritise the establishment of residential services, such as group homes, but focuses on supporting children to grow up in a family?

Article 10 - Right to life

Failure to protect the right to life in institutional settings

Deaths in European institutions highlight the systemic failure to protect the right to life of disabled people detained in various kinds of institutions, including nursing homes, group homes, social care homes for children and adults, and psychiatric institutions. The widespread practice of locking people in their rooms and using physical restraints puts their lives in grave danger during emergencies. In January 2022, six people died and a further 17 were hospitalised when a fire broke out in a Spanish nursing home which housed 70 people²⁷. In November 2021, nine people were killed in a fire at a Bulgarian nursing home of 58 people²⁸. In January 2020, six people died when a fire broke out in a Czech nursing home which housed 20 people²⁹. In 2020, eight disabled people died and 30 more were injured in a fire at a Czech institution which housed 35 disabled people³⁰. This tragedy occurred shortly after a report by the Czech Ombudsman, which found that disabled people were locked in their rooms at night, warning that 'in the event of a fire, staff, of which there are only a minimal number at night, would have to bypass and unlock all parts of the facility in order to evacuate the clients'³¹. In 2015, three people who were tied to their beds lost their lives when a fire

²⁶ Validity (2021). Deinstitutionalisation and life in the community in Bulgaria: A three-dimensional illusion, p.21. Available at: <https://validity.ngo/wp-content/uploads/2021/09/Deinstitutionalisation-and-Life-in-the-Community-in-Bulgaria-FINAL.pdf>.

²⁷ The Washington Post (2022). Nursing Home Fire Kills 6, Hospitalises 17 in Eastern Spain. Available at https://www.washingtonpost.com/world/nursing-home-fire-kills-5-in-eastern-spain/2022/01/19/d6e3faf0-78f7-11ec-9dce-7313579de434_story.html

²⁸ Reuters (2021) Fire at nursing home in Bulgaria kills 9 people. Available at <https://www.reuters.com/world/europe/fire-nursing-home-bulgaria-kills-9-people-2021-11-22/>.

²⁹ ABC News (2020). Fire engulfs nursing home in Croatia, at least 6 dead Available at <https://abcnews.go.com/International/wireStory/fire-engulfs-nursing-home-croatia-reported-dead-68212825>.

³⁰ BBC News (2020). Czech fire: Eight killed at disabled people's home in Vejpřty. Available at <https://www.bbc.com/news/world-europe-51166732>.

³¹ Ombudsman (2020). Homes for people with disabilities are not homes. Available at: <https://www.ochrance.cz/aktualne/domovy-pro-osoby-s-postizenim-nejsou-domovem/>

broke out at a Greek psychiatric hospital ³².

Failure to protect the right to life during the COVID-19 pandemic

Emergency human rights monitoring that was conducted by disabled people's organisations (DPOs) during the COVID-19 pandemic gathered empirical evidence of grave and systemic violations of fundamental freedoms and human rights of disabled people confined to large and small institutions throughout Europe³³. Inadequate measures to protect the lives, health and safety of persons confined to institutions are reflected in the disproportionate number of COVID-19 related deaths^{34 35}. For example, deaths in nursing homes account for 51% of the total COVID-19 deaths in the Netherlands³⁶ and 68% of COVID related deaths in Spain³⁷. Even in death, disabled people in institutions were denied their inherent dignity. For instance, in the Madrid district of Usera, the bodies of two nursing home residents who had died from the virus were left in their rooms for almost an entire day before their bodies were collected³⁸.

EU funds risking lives by supporting institutions

Despite the threat to life within overcrowded institutions, EU funds are supporting the proliferation of large institutions in Europe. For instance, Poland has used 7 million EUR of the European Regional and Development Fund (ERDF) on institutional settings for disabled people, including a 4-storey building for approximately 90 people in Łódź and the extension and conversion of an 80-person social care home in Drzewica. ³⁹

Multi-million investments are going ahead despite the devastating death rates associated with overcrowding, abuse, and neglect in nursing homes. Backed by the Investment Plan for Europe (Juncker plan), the European Investment Bank (EIB) approved multi-million loans to various companies for the expansion of nursing homes⁴⁰. There are reports that European-backed funds are supporting nursing homes

³² Ekathimerini (2015). Questions linger in Dafni hospital deaths. Available at

<https://www.ekathimerini.com/news/201287/questions-linger-in-dafni-hospital-deaths/>

³³ COVID-19 Disability Rights Monitor (2020). Disability rights during the pandemic A global report on findings of the COVID-19 Disability Rights Monitor Available at <https://covid-drm.org/assets/documents/Disability-Rights-During-the-Pandemic-report-web.pdf>

³⁴ Danis, K., Fonteneau, L., Georges, S., Daniau, C., Bernard-Stoecklin, S., Domegan, L., ... & Schneider, E. (2020). High impact of COVID-19 in long-term care facilities, suggestion for monitoring in the EU/EEA, May 2020. *Eurosurveillance*, 25(22), 2000956.

³⁵ Comas-Herrera, A., Zalakaín, J., Lemmon, E., Henderson, D., Litwin, C., Hsu, A. T., ... & Fernández, J. L. (2020). Mortality associated with COVID-19 in care homes: international evidence. *Article in LTCcovid.org, international long-term care policy network, CPEC-LSE, 14*.

³⁶ Comas-Herrera, A. et al (2021). Mortality associated with COVID-19 in care homes: international evidence. *International Long-Term Care International*.

³⁷ Comas-Herrera, A. et al. (2020). Mortality associated with COVID-19 in care homes: international evidence. *Article in LTCcovid.org, international long-term care policy network, CPEC-LSE, 14*.

³⁸ Rada. A. G. (2020) Covid-19: the precarious position of Spain's nursing homes. *British Medical Journal* doi: 10.1136/bmj.m1554.

³⁹ ENIL and Validity (2020). Complaint – Infringement of EU law. Available at https://enil.eu/wp-content/uploads/2020/08/Complaint_Poland.pdf

⁴⁰ The European Commission is a major shareholder in the European Investment Fund, which is a subsidiary of the EIB. The European Commission nominates a member of the Board of Directors and expresses an opinion on every project presented to the Board of Directors.

that practice locking residents inside their rooms. For instance, reports from Spain suggest that dangerous human rights abuses occurred within nursing homes run by the Vitalia group, when the residents in this institution were locked in their rooms during COVID-19 outbreaks⁴¹. The EIB has invested heavily in the nursing homes under investigation. EIB intends to provide grants of EUR 57.5m to Vitalia Home to build 19 retirement homes, which will provide 3200 residential places for 'groups of 15 to 20 elderly people' in Spain⁴². The Vitalia group also run residential institutions for disabled people⁴³.

Suggested question for the LOIPR:

- What measures will the EU take to prevent EU-backed investments in institutions, including nursing homes which are at the centre of gross human rights violations, including denial of the right to life?

Article 11 - Situations of risk and humanitarian emergencies

EU Funding inherently dangerous institutions

Emergency human rights monitoring at the beginning of the COVID-19 pandemic exposed the systematic failure to provide a disability-inclusive response to protect disabled people confined to institutions. The most basic safety measures were not implemented in institutions, which failed to provide personal protective equipment (PPE) and adequate sanitation⁴⁴.

The human rights violations recorded during the COVID-19 pandemic, although significant, are not an isolated incident⁴⁵. Disabled people confined to institutions are

⁴¹ Cronica (2020). Una residencia encierra a 190 mayores en Barcelona por síntomas de Covid-19. Available at https://cronicaglobal.elespanol.com/vida/vitalia-coronavirus-ancianos-covid-19-mayores_330867_102.html

⁴² European Investment Bank (2019). Spain: EIB grants EUR 57.5m to Vitalia Home to build 19 retirement homes <https://www.eib.org/en/press/all/2019-374-eib-grants-eur-575m-to-vitalia-home-to-build-19-retirement-homes>

⁴³ Vitaliahome (2021). Centros para personas con discapacidad. <https://www.vitaliahome.es/personas-con-discapacidad/>

⁴⁴ COVID-19 Disability Rights Monitor (2020). Disability rights during the pandemic A global report on findings of the COVID-19 Disability Rights Monitor Available at <https://covid-drm.org/assets/documents/Disability-Rights-During-the-Pandemic-report-web.pdf>.

⁴⁵ Shakespeare, T., Ndagire, F., & Seketi, Q. E. (2021). Triple jeopardy: disabled people and the COVID-19 pandemic. *Lancet (London, England)*.

inherently exposed to natural disasters, hazards, and infectious diseases^{46 47 48 49 50}. On July 15th, 2021, 12 disabled people lost their lives in a German group home during severe flooding. Yet, despite the immediate risk, the EU funds continue to support the building of institutions in high-risk areas. For example, ESI Funds have been used to build institutions on flood plains in Hungary (Táplánszentkereszt).

Disabled people are not meaningfully involved in disaster risk planning

Disaster risk management is one critical area in where the EU does not provide adequate consultation with disabled people and their representative organisations. The European Commission has endorsed the Charter on Inclusion of Persons with Disabilities in Humanitarian Action (2016) which recognises that ‘persons with disabilities and their representative organizations have untapped capacity and are not sufficiently consulted nor actively involved in decision-making processes concerning their lives, including in crisis preparedness and response coordination mechanisms’⁵¹. Yet, the EU has not meaningfully engaged with disabled people and their representative organisation on disaster risk reduction. Despite warnings from disabled people and their representative organisations about the inherent dangers of large and small institutions, ESI Funds are being used to build institutions that put disabled people at unnecessary risk of natural disasters, hazards, and the spread of infectious disease.

Suggested questions for the LOIPR:

- How will the EU meaningfully consult and involve disabled people and their representative organisations in planning for the adoption of a risk-informed approach into all EU policies and programmes?
- How will the EU ensure that EU funds are not used to build or renovate large and small institutions which inherently and unnecessarily expose disabled people to disasters and hazards?

⁴⁶ Priestley, M., & Hemingway, L. (2007). Disability and disaster recovery: a tale of two cities?. *Journal of Social Work in Disability & Rehabilitation*, 5(3-4), 23-42

⁴⁷ Hemingway, L., & Priestley, M. (2006). Natural hazards, human vulnerability and disabling societies: A disaster for disabled people?. *Review of Disability Studies: An International Journal*, 2(3).

⁴⁸ Fox, M. H., White, G. W., Rooney, C., & Rowland, J. L. (2007). Disaster preparedness and response for persons with mobility impairments: Results from the University of Kansas Nobody Left Behind Study. *Journal of Disability Policy Studies*, 17(4), 196-205.

⁴⁹ Mladenov, T., & Brennan, C. S. (2021). Social vulnerability and the impact of policy responses to COVID-19 on disabled people. *Sociology of Health & Illness*.

⁵⁰ Shakespeare, T., Ndagire, F., & Seketi, Q. E. (2021). Triple jeopardy: disabled people and the COVID-19 pandemic. *Lancet (London, England)*.

⁵¹ Charter of inclusion of persons with disabilities in humanitarian action. (2016). Available at <http://humanitariandisabilitycharter.org/>

Article 12 - Equal recognition before the law

Guardianship is widely used across Europe

Following the ratification of the CRPD, many EU Member States took steps to align their policies and legislation with the requirements of Article 12. However, there are still countries where legislation does not support the exercise of legal capacity by disabled people⁵² or where progress has been reversed by the adoption of new legislation, reintroducing guardianship⁵³. Even in countries where alternatives to guardianship have been developed, they are rarely used, with guardianship continuing to be a norm rather than exception (for example, Belgium⁵⁴ Netherlands⁵⁵, and France⁵⁶). In Hungary, which was among the first countries to initiate reforms of its legal capacity legislation, there has been a steady increase in the number of people under guardianship⁵⁷.

Limited promotion of supported decision-making at EU level

Many disabled people living in institutions in the EU are deprived of legal capacity, wholly or partially, and not allowed to make decisions about whether and with whom to live⁵⁸. The decision about their institutionalisation has been made by a guardian, usually a relative, often against the persons' will or without their informed consent. In some cases, the placement of disabled people in institutions has been motivated by relatives' own interests, for example, concerning property ownership⁵⁹. At the same time, the deprivation of legal capacity and the lack of direct access to the justice system often means disabled people are unable to leave institutions⁶⁰. Thus, deprivation of

⁵² Georgieva, S. (2021). Bulgaria e edinstvenata durjava v ES, koiato zabraniava hora [Bulgaria is the only country in the world banning people], SEGA, published on 31 June 2021. Available at: <https://www.segabg.com/category-observer/bulgariya-e-edinstvenata-durzhava-es-koyato-zabranyava-hora>

⁵³ Panayotova, K. (2018). Open letter about the process of deinstitutionalisation in Croatia. http://enil.eu/wp-content/uploads/2018/04/Croatia_April2018_final.pdf.

⁵⁴ ENNHRI and MHE (2020). Implementing supported decision-making: Developments across Europe and the role of National Human Rights Institutions. Available at: <http://ennhri.org/wp-content/uploads/2020/06/8-June-2020-Implementing-supported-decision-making-Developments-across-Europe-and-the-role-of-NHRIs.pdf>

⁵⁵ Stelma-Rooda, H., Blankman, C., and Antokolskaia, M. (2019). 'A changing paradigm of protection of vulnerable adults and its implications for the Netherlands'. *Family and Law*, February 2019. Available at: <http://www.familyandlaw.eu/tijdschrift/fenr/2019/02/FENR-D-18-00006>.

⁵⁶ Special Rapporteur on the rights of persons with disabilities (2019). Visit to France, Report of the Special Rapporteur on the rights of persons with disabilities. Available at: <https://undocs.org/en/A/HRC/40/54/Add.1>

⁵⁷ Committee on the Rights of Persons with Disabilities (2019). Inquiry concerning Hungary carried out by the Committee under article 6 of the Optional Protocol to the Convention, para. 25. Available at: https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fHUN%2fIR%2f1&Lang=en.

⁵⁸ FRA (2018). From institutions to community living: perspectives from the ground, p. 44. Available at: https://fra.europa.eu/sites/default/files/fra_uploads/fra-2018-from-institutions-to-community-living-ground-perspectives_en.pdf.

⁵⁹ Ibid.

⁶⁰ Py, M. (2020). The invisible half-citizens in the country of the Human rights declaration. ENIL, 31 January 2020. Available at: <https://enil.eu/news/the-invisible-half-citizens-in-the-country-of-the-human->

legal capacity both leads to institutionalisation and hinders deinstitutionalisation and independent living by preventing disabled people from making choices about their lives.

While the EU has limited competencies in relation to legal capacity, it could take steps to promote a shift towards supported decision-making, for example, by raising awareness and supporting research and exchange of good practices. The EU has not used the opportunity provided by the midterm review of the European Disability Strategy 2010-2020 to revise the strategy and step up its efforts in the area of legal capacity. The new EU Strategy for the Rights of Persons with Disabilities 2021-2030⁶¹ also pays limited attention to issues related to legal capacity and supported decision-making. Furthermore, it is concerning that the Strategy supports the ratification of the 2000 Hague Convention, which ‘deeply relies on limitations of legal capacity that the CRPD prohibits’⁶². Concerns have also been raised about the lack of involvement of DPOs in the discussions concerning the ratification of the 2000 Hague Convention by the EU Member States⁶³.

Suggested questions for the LOIPR:

- How does the EU plan to ensure that the implementation of the 2000 Hague Convention will not involve measures contradictory to the CRPD?
- How will the EU ensure that disabled people are not denied access to justice, due to deprivation of legal capacity?
- What specific measures will the EU take to promote supported decision-making?

Article 14 - Liberty and security of persons

Detention in institutions

Throughout Europe, disabled people young and old are deprived of their liberty and detained against their will in institutions. Physical restraints are commonly used. For instance, straightjackets were found in institutions partially funded by the European

[rights-declaration/](#); Oláh, E. (2019). Bulgarian court finds guardian responsible for harm of forced institutionalisation. Validity, 15 May 2019. Available at: <https://validity.ngo/2019/05/15/bulgarian-court-finds-guardian-responsible-for-harm-of-forced-institutionalisation/>.

⁶¹ EC (2021). Union of equality: Strategy for the rights of persons with disabilities. Available at: <https://ec.europa.eu/social/main.jsp?catId=738&langId=en&pubId=8376&furtherPubs=yes>.

⁶² Schefer, M. (2021). Comments on the EU Strategy. Available at: https://www.markusschefer.ch/admin/data/files/asset/file_en/18/speech-eu-strategy-2021-04-19.pdf?lm=1622378987.

⁶³ EDF (2021). Persons with disabilities not included in EU’s discussion on “vulnerable adults”. Available at: <https://www.edf-feph.org/persons-with-disabilities-not-included-in-eus-discussions-on-vulnerable-adults/>.

Union⁶⁴.

Nursing homes have been criticised for locking doors in the name of ‘safety’⁶⁵. A Spanish study estimated that 85% of residents in Spanish nursing homes had been physically restrained⁶⁶. Deprivation of liberty intensified during the COVID-19 pandemic, with reports that people in nursing homes were locked in their rooms in countries including Finland⁶⁷, the Republic of Ireland, Spain, and Italy. This left disabled people exposed to abuse and exploitation. For instance, in Ireland, a woman with Alzheimer’s was raped by a worker while she was confined to her room during the pandemic⁶⁸.

The human rights violations reported in nursing homes also impact young disabled people. Figures for the numbers of young disabled people confined to nursing homes in Europe are scarce. Hence, disabled people in nursing homes remain hidden across the EU. A recent report by the Office of the Ombudsman in the Republic of Ireland reported that there are at least 1,300 disabled people under 65 years old confined to nursing homes⁶⁹. The high proportion of disabled young people in Irish nursing homes is a result of the chronic underfunding of personal assistance and the prioritisation of nursing home care, which has received multi-million investments⁷⁰. Hence, young disabled people live with the constant threat of institutionalisation within nursing homes⁷¹. A recent decision by the Department of Enterprise excludes home carers from the critical skills exemption to the non-EEA employment permit system⁷². As a result, the Irish government are actively encouraging staff into the nursing home sector, resulting in the chronic understaffing of personal assistance and home care initiatives.

⁶⁴ MDAC (2017). Straightjackets and seclusion. An investigation into abuse and neglect of children and adults with disabilities in Hungary. Available at http://www.mdac.org/sites/mdac.info/files/straightjackets_and_seclusion_-_mdac.pdf

⁶⁵ Cahill, S. (2018). Dementia and human rights. Policy Press.

⁶⁶ Estévez-Guerra, G. J., Fariña-López, E., Núñez-González, E., Gandoy-Crego, M., Calvo-Francés, F., & Capezuti, E. A. (2017). The use of physical restraints in long-term care in Spain: a multi-center cross-sectional study. *BMC geriatrics*, 17(1), 1-7.

⁶⁷ Parliamentary Ombudsman of Finland (2020). Deputy-Ombudsman concerned by the lack of guidelines for and supervision of elderly care - Press releases. https://www.oikeusasiamies.fi/en_GB/-/apulaisoikeusasiamies-huolissaan-vanhustenhuollon-ohjeistusten-ja-valvonnan-puutteista

⁶⁸ Irish Times (2020). Healthcare assistant jailed for rape of elderly woman in nursing home <https://www.irishtimes.com/news/crime-and-law/courts/criminal-court/healthcare-assistant-jailed-for-rape-of-elderly-woman-in-nursing-home-1.4317757>

⁶⁹ Wasted Lives. Time for a Better Future for Younger People in Nursing Homes (2021). <https://www.ombudsman.ie/publications/reports/wasted-lives/OMBWastedLives2021.pdf>

⁷⁰ Bank of Ireland (2021). Sectors Team Nursing Home Sector 2020 Insights / Outlook 2021 <https://businessbanking.bankofireland.com/app/uploads/BOI-Sectors-Team-Nursing-Homes-Insights-and-Outlook-2021.pdf>

⁷¹ Irish Times (2018). Young people with disabilities are ‘being trapped in nursing homes’. Available at <https://www.irishtimes.com/news/social-affairs/young-people-with-disabilities-are-being-trapped-in-nursing-homes-1.3525778>

⁷² Irish Times (2021). Man with MS fears being sent to nursing home after home care hours removed. Available at <https://www.irishtimes.com/news/ireland/irish-news/man-with-ms-fears-being-sent-to-nursing-home-after-home-care-hours-removed-1.4724907>

EU-backed funding institutions depriving liberty

Despite the dangers posed by nursing homes, the EIB continues to invest heavily in these institutions. Recently, the EIB approved a €100 million loan to the Zuyderland Group in the Netherlands⁷³. The Zuyderland Group provides a range of medical services including the construction of 14 homes for people with dementia, which will house up to two groups of 7 people⁷⁴. The EIB has also promised €200 million for projects consisting of ‘construction, refurbishment or enlargement of existing social and long-term care facilities across Portugal... aims at delivering continued care services to elderly people and people with disabilities’⁷⁵.

Suggested questions for the LOIPR:

- What measures will the European Union take to ensure that European-backed investments do not fund institutions that deprive disabled people of their right to liberty?
- What measures will the European Union take to ensure that abuses such as the use of straightjackets and locked doors policies do not occur in institutions?

Article 15 - Freedom from torture or cruel, inhuman, or degrading treatment or punishment

Use of torture in EU-funded institutions

Overwhelming evidence of torture throughout European institutions strongly indicates that it is a systemic issue in the EU. For instance, there is video evidence of the use of chemical and physical restraints, solitary confinement and cages in Greek and Slovak institutions^{76 77}. A child with autism was taped to a chair and tied to a bed for more than 5 years in a Finnish institution that houses up to 11 people⁷⁸.

European Union funds have been used in institutions at the centre of gross human rights violations. For instance, ESI Funds were used to fund a 220-bed institution which was found to use metal cage beds and straightjackets for adults and children in Göd,

⁷³ Devdiscourse (2021). Netherlands: EIB signs €100m loan with Zuyderland Group to renew hospital facilities. Available at <https://www.devdiscourse.com/article/business/1837836-netherlands-eib-signs-100m-loan-with-zuyderland-group-to-renew-hospital-facilities>

⁷⁴ Zuyderland (2020). New construction Parc Glana. Available at <https://www.zuyderland.nl/zorg/nieuwbouw/>

⁷⁵ European Investment Bank. (2022). Elderly care investment in Portugal. Available at <https://www.eib.org/en/projects/pipelines/all/20180273>

⁷⁶ The Greek Ombudsman (2011). Functioning Conditions of the Social Care Center for children with disabilities <https://www.synigoros.gr/resources/docs/kepeplechaina2011.pdf>

⁷⁷ Committee against Torture (2021). Decision adopted by the Committee under article 22 of the Convention, concerning communication No. 890/2018. Available at <https://validity.ngo/wp-content/uploads/2021/12/CAT-C-72-D-890-2018-English-clean-copy.pdf>

⁷⁸ YLE. (2021). Days taped to a chair and nights with loads attached to bed – unlawful treatment and abuse of a mentally disabled boy in a care home was allowed to continue for years. Available at <https://yle.fi/uutiset/3-12175567>

Hungary⁷⁹.

Suggested question for the LOIPR:

- How will the EU ensure that EU funding does not support institutions that practice torture including the use of cage beds and straightjackets, and other forms of physical and chemical restraints?

Article 18 - Freedom of movement

Lack of portability of social assistance benefits

The enjoyment of the right to free movement of disabled people is limited by the lack of portability of social assistance benefits and the restrictions on the possibility to claim such benefits in the host state within the EU. While there is coordination among EU Member States in relation to social security benefits (for example, sickness and unemployment benefits and pensions), which allows cash benefits from one country to be exported to another, there is no such coordination with regard to social assistance benefits, under which personal assistance falls. At the same time, access to social assistance of people moving to another Member State is limited by requirements related to their employment status or length of stay in the host country⁸⁰. Even if a person is in principle eligible to access social assistance in the host state (for example, because they are employed or a family member of a worker), they might need to undergo a long assessment process, which would leave them without support for a considerable period of time. In addition, the requirement for people to be working in order to access social assistance puts those disabled people who require additional support to engage in employment in an unequal position.

The negative impact of the existing arrangements on the free movement of disabled people can be illustrated by the very low levels of participation of students with additional support needs in the Erasmus programme, supporting students to study abroad. While the programme promotes mobility for all, the percentage of students receiving additional support needs supplement is between 0.11 and 0.15%⁸¹. In addition, the share of disabled students undertaking mobility out of all disabled students in a Member State is close to zero, with no outgoing students from some countries in some years⁸².

⁷⁹ MDAC (2017). Straightjackets and seclusion. An investigation into abuse and neglect of children and adults with disabilities in Hungary. Available at http://www.mdac.org/sites/mdac.info/files/straightjackets_and_seclusion_-_mdac.pdf

⁸⁰ They need to be workers or self-employed; if economically inactive, to have lived in the host country for five years.

⁸¹ SIHO (2020). Making mobility programmes more inclusive for students with disabilities. Available at: https://www.siho.be/sites/default/files/making_mobility_programmes_more_inclusive_for_students_with_disabilities.pdf.

⁸² Benedictis, L. and Leoni, S. (2021). 'Inclusive universities: evidence from the Erasmus program'. *Applied Network Science*, 6, 83. Available at: <https://doi.org/10.1007/s41109-021-00419-x>.

ENIL welcomes the EC's commitment to expand the geographical coverage and the scope of the European Disability Card⁸³, expressed in the new EU disability strategy (2021-2030). While it is still not clear how the card will function, ENIL is concerned that the limited scope of the entitlements included and participation by Member States or service providers could hinder the potential of the card to support the freedom of movement of disabled people.

Suggested questions for the LOIPR:

- How will the EU encourage Member States to recognise the European Disability Card?
- Does the EU plan to expand the scope of the European Disability Card to cover disability benefits?

Article 19 - Living independently and being included in the community

Investment of EU funds in large institutions for disabled people

ESI Funds continue to be invested in building and renovating large institutions for disabled people. For example, in the 2014-2020 programming period, the Łódź Voivodeship in Poland used resources from the European Regional Development Fund to build, expand or renovate institutions for disabled people with 80-90 residents⁸⁴. The Region of Attika, Greece, while including deinstitutionalisation in its strategy for social inclusion, has planned to enhance the infrastructure and programmes of institutions with support from the ESI Funds⁸⁵.

Funds from the Recovery and Resilience Facility, an instrument aimed to support EU's recovery from COVID-19, are also being invested in large and small institutions in many EU Member States, including Croatia, France, the Czech Republic, and Latvia⁸⁶.

EU Funds support the proliferation of group homes and other segregating residential settings

Despite the prohibition of using public or private funds to maintain institutions, required by the CRPD, in the last 10 years, there has been a **proliferation of group homes** for disabled people in the EU. In many countries, this has been supported with resources from ESI Funds, for example in Austria, Bulgaria, Croatia, the Czech Republic, Estonia,

⁸³ The Card was piloted as a voluntary initiative in 8 EU member states between 2016-2019, but only covered the areas of culture, leisure, sports and transportation.

⁸⁴ ENIL and Validity (2020) Complaint – Infringement of EU law. Available at: https://enil.eu/wp-content/uploads/2020/08/Complaint_Poland.pdf

⁸⁵ Strati, E. (2018) Living independently and being included in the community: Greece. Country report. Available at: <https://www.disability-europe.net/downloads/1000-year-4-2018-19-policy-theme-il>.

⁸⁶ EEG (2021) EEG's main findings on the submitted Recovery & Resilience National Plans. Available at: <https://deinstitutionalisationdotcom.files.wordpress.com/2021/09/summary-of-the-findings-final-rr-plans-1.pdf>.

Greece, Hungary, Lithuania, Malta, Poland, Portugal, Romania and Slovenia^{87 88}. The availability of EU funding for group homes and the lack of restrictions concerning investment of EU money in such settings has provided an incentive to build new group homes in some countries. In 2020, the UN Special Rapporteur on the rights of persons with disabilities and the Special Rapporteur on adequate housing wrote to the President of the European Council to express their concern at the continued use of European funding to maintain institutionalisation, by replacing large institutions with smaller institutions⁸⁹.

Group homes (and other similar settings, such as community centres and protected or supported houses) are often created as *the* main alternative to traditional large-scale institutions in EU-supported programmes for deinstitutionalisation. For example, in Lithuania, the plans for ‘deinstitutionalisation’ involve moving 2,700 – 3,000 disabled people (out of approximately 6,500 living in social care institutions) to group homes and similar small institutions⁹⁰, for which the government has designated 26,5 million Euro from ESI Funds and 6 million from the state. CRPD Committee’s inquiry concerning Hungary, completed in 2020, found that the investment of ‘significant amount of resources’, including from ESI Funds, in moving people from large to small group homes has sustained and expanded the institutionalisation of disabled people and has thus prevented their inclusion in the society⁹¹. In the concluding observations on Poland, the CRPD Committee expressed concerns about ‘[t]he spending of European Union funds allocated to deinstitutionalization on measures that are not

⁸⁷ ENIL (2020). Lost in interpretation: the use of ESI Funds during 2014-2020 and the impact on the rights of persons with disabilities to independent living, p.27. Available at: https://enil.eu/wp-content/uploads/2020/12/Study_EP_EN_09122020.pdf.

⁸⁸ ENIL (2018). Briefing on the Use of EU Funds for Independent Living. Available at: http://enil.eu/wp-content/uploads/2018/04/EU-Funds-Briefing_web0903.pdf.

⁸⁹ UN Special Rapporteur on the Rights of Persons with Disabilities, Ms. Catalina Devandas-Aguilar, and the UN Special Rapporteur on the Right to Adequate Housing (2020). Available at: <https://spcommreports.ohchr.org/TMResultsBase/DownloadPublicCommunicationFile?gld=25267>

⁹⁰ ENIL (2020). Lost in interpretation: the use of ESI Funds during 2014-2020 and the impact on the rights of persons with disabilities to independent living, p.26.

⁹¹ Committee on the Rights of Persons with Disabilities (2019) Inquiry concerning Hungary carried out by the Committee under article 6 of the Optional Protocol to the Convention. Available at: https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fHUN%2fIR%2f1&Lang=en, para 1b.

consistent with the Convention⁹². Estonia⁹³, Lithuania⁹⁴ and Bulgaria⁹⁵ have also received recommendations from the CRPD Committee urging them to re-direct the investment of EU funds to the development of individualised support and away from institutions and congregated settings.

In a number of countries (for instance, Estonia, Latvia, and Slovenia), the creation of group homes has been presented as a temporary step in the process of transition from large institutions to life in the community, justified with the ‘difficulties in immediate integration of former residents of large institutions into communities’⁹⁶. The EC has defended the substantial investments of EU money in such settings arguing that they ‘may serve to achieve the aim to progress towards community-based living’ because ‘[b]efore (full) de-institutionalisation is achieved, the persons concerned have, however, to be cared for’⁹⁷. Due to the lack of commitment and the insufficient and uneven development of other support options in the community, such arrangements typically become long-term or permanent. A recent study on the right to live independently and being included in the community in European states⁹⁸ confirms that it has not found an example where a timeframe has been placed on the use of such settings, emphasising that they are ‘a common living arrangement’ and continue to be developed in many countries where large-scale institutions have been closed (for example, Denmark).

There are also many cases where **clusters of group homes or other residential settings** have received ESI Funds, reinforcing the segregation and isolation of

⁹² Committee on the Rights of Persons with Disabilities (2018). Concluding Observations Poland Available at: https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fPOL%2fCO%2f1&Lang=en.

⁹³ Committee on the Rights of Persons with Disabilities (2016) Concluding observations on the initial report of Estonia, CRPD/C/EST/CO/1. Available at: https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fEST%2fCO%2f1&Lang=en.

⁹⁴ Committee on the Rights of Persons with Disabilities (2016) Concluding observations on the initial report of Lithuania, CRPD/C/LTU/CO/1. Available at: https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fLTU%2fCO%2f1&Lang=en.

⁹⁵ Committee on the Rights of Persons with Disabilities (2016) Concluding observations on the initial report of Bulgaria, CRPD/C/BGR/CO/1. Available at: https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fBGR%2fCO%2f1&Lang=en.

⁹⁶ Pall, K. and Leppik L. (2018). Living independently and being included in the community. Country report, Estonia. Available at: <https://www.disability-europe.net/downloads/1026-year-4-2018-2019-policy-theme-il>.

⁹⁷ REGIO.B.4/ (2021) Your Complaint registered under CHAP(2019)3555, letter to Mrs Bulic Cojocariu Ines, ref. Ares(2021)2617310-19/04/2021.

⁹⁸ Crowther, N. (2019). The right to live independently and be included in the community in European states. ANED synthesis report. Available at: <https://www.disability-europe.net/downloads/1040-task-year-4-2018-19-policy-theme-il-synthesis-report>.

disabled people (for example, in Estonia⁹⁹, Hungary¹⁰⁰, and Poland¹⁰¹). In Malta, despite the objections from disabled people, the Commission for the Rights of Persons with Disabilities and the CRPD Committee, a ‘community hub’ for disabled people is being built with four blocks, comprised of ‘semi-independent living residential units, a community building, restaurant and cafeteria, a retail outlet, offices, gym and therapy pool’¹⁰². The investment in the hub is 39 million EUR, of which 9 million come from ESI Funds. Such practices are not in line with Article 19.

There are also many examples from the EU demonstrating **the institutional character of group homes**. In Hungary, disabled people living in supported houses have no influence over the services and support they receive¹⁰³. Their autonomy and self-determination are further restricted by the requirement to obtain permission for inviting guests or engaging in activities outside the setting¹⁰⁴. In Estonia, group homes have fixed timetables, including for getting up and going to bed and mealtimes, and residents need permission from staff to use the kitchen or house telephone¹⁰⁵. In some countries, group homes additionally limit disabled people’s choice by providing housing and support in one package or by not ensuring adequate choice of providers of support (for example, Bulgaria, Hungary). According to the General Comment No. 5, “package solutions” which, among other things, link the availability of one particular service to another, expect two or more persons to live together or can only be provided within special living arrangements are not in line with article 19¹⁰⁶.

It is important to emphasise that the institutional character of group homes is not simply a consequence of inadequate funding or training of staff, as it is sometimes suggested; it is related to the very nature of these settings. As the Council of Europe Human Rights Commissioner notes, a person living in a group home ‘has little chance of choosing

⁹⁹ ENIL (2017) So close, yet so far. Available at: http://enil.eu/wp-content/uploads/2017/10/DisabilityWatchdog_Estonia_Oct2017_Final.pdf

¹⁰⁰ Crowther, N., Quinn, G., Hillen-Moore, A. (2017). Opening up communities, closing down institutions: Harnessing the European Structural and Investment Funds. Community Living for Europe, Structural Funds Watch, p. 21. Available at:

https://eustructuralfundswatchdotcom.files.wordpress.com/2017/11/cle-sfw_opening-up-communities-november-2017_final.pdf.

¹⁰¹ Opening Doors for Europe’s Children (2016). Poland. Country Factsheet. Available at: <https://www.openingdoors.eu/wp-content/uploads/2016/12/poland-1.12.pdf>

¹⁰² Magri, G. (2019) Updated: Government aims to open Naxxar community hub for persons with disability in 2022. *Malta Independent*, 22 July 2019. Available at: <https://www.independent.com.mt/articles/2019-07-22/local-news/Government-aims-to-open-Naxxar-community-hub-for-persons-with-disability-in-2022-6736211210>

¹⁰³ Gazsi, 2018, quoted in Gyulavári, T, Gazsi, A. and Matolcsi, R. (2019). Living independently and being included in the community. Country report: Hungary. Available at: <https://www.disability-europe.net/downloads/1002-year-4-2018-19-policy-theme-il>.

¹⁰⁴ Committee on the Rights of Persons with Disabilities (2019) Inquiry concerning Hungary carried out by the Committee under article 6 of the Optional Protocol to the Convention, para 68. Available at: https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fHUN%2fIR%2f1&Lang=en

¹⁰⁵ ENIL (2017). So close, yet so far. Available at: http://enil.eu/wp-content/uploads/2017/10/DisabilityWatchdog_Estonia_Oct2017_Final.pdf.

¹⁰⁶ General comment No. 5

her housemates or having privacy within her home. Because the house is run for a large group, and especially if she needs support for daily living or in accessing the community, she will likely be subject to restrictions that impede possibilities for a self-directed life, including rules about when she can leave and with whom and how often, and when to retire for the night¹⁰⁷.

There is also evidence of **financial irregularities in the use of ESI Funds**. For instance, a Romanian NGO has collected disturbing information about the misuse of European money for deinstitutionalisation: prices well above the maximum cost standard for the construction of smaller institutions, so-called 'protected housing' projects have been delayed or even non-existent¹⁰⁸.

Inadequate development of community services

The limited availability of adequate community support options, in line with Article 19, forces many disabled people to 'choose' residential care. For example, in the Netherlands, the shortage of accessible and affordable housing options in some municipalities makes it difficult for disabled people to choose their place of residence or to leave residential settings¹⁰⁹. In the Czech Republic, personal assistance is often only provided for up to 4-5 hours a day, during the standard daily working hours, making it impossible for disabled people without informal support to avoid institutionalisation¹¹⁰. In some countries, there has been a trend towards re-institutionalisation; for example, as a result of the decrease of state-funded personal assistance (Sweden¹¹¹) or the lack of community-based services and financial assistance for young people leaving foster care (Greece¹¹²).

Although a significant amount of EU money has been allocated to support the development of community-based services, the parallel investment in small and large

¹⁰⁷ Commissioner for Human Rights (2012). Issue paper on the rights of persons with disabilities to live independently and to be included in the community. Available at: <https://rm.coe.int/the-right-of-people-with-disabilities-to-live-independently-and-be-inc/16806da8a9>.

¹⁰⁸ [Centrul de Resurse Juridice](https://www.crj.ro/pledoarie-pentru-demnitare/asiurarea-protectiei-drepturilor-persoanelor-cu-dizabilitati-intelectuale-si-psihosociale-aflata-in-situatii-de-risc-pledoarie-pentru-dreptul-la-sanatate-si-la-viata-independenta/harta-fondurilor-europene-pentru-dezinstitutionalizare/). (2021). Unde sunt banii Europeni pentru deinstitutionalizarea persoanelor cu dizabilitati? Available at <https://www.crj.ro/pledoarie-pentru-demnitare/asiurarea-protectiei-drepturilor-persoanelor-cu-dizabilitati-intelectuale-si-psihosociale-aflata-in-situatii-de-risc-pledoarie-pentru-dreptul-la-sanatate-si-la-viata-independenta/harta-fondurilor-europene-pentru-dezinstitutionalizare/>

¹⁰⁹ Netherlands Institute for Human Rights (2018). Submission to the Committee on the Rights of Persons with Disabilities Concerning the initial report of the Netherlands. Available at: https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=INT%2fCRPD%2fIFN%2fNLD%2f33287&Lang=en.

¹¹⁰ Angelova-Mladenova, L. (2019) Seminar 'Moving towards independent living and community-based care - EU funding instruments to support the development of community-based services for persons with disabilities: personal assistance and personal budgets', thematic comparative paper. Available at: <https://ec.europa.eu/esf/BlobServlet?docId=21341&langId=en>.

¹¹¹ Commissioner for Human Rights (2018). Report by Nils Muižnieks, Commissioner for human rights of the Council of Europe following his visit to Sweden from 2 to 6 October 2017. CommDH(2018)4. Available at: <https://rm.coe.int/commdh-2018-4-report-on-the-visit-to-sweden-from-2-to-6-october-2017-b/16807893f8>.

¹¹² Opening Doors for Europe's Children (2018). Greece. 2018 Fact sheet. Available at: <https://eurochild.org/uploads/2022/01/Opening-Doors-country-fiche-Greece-2018.pdf>.

residential settings has been a hindrance to the development of alternative housing and support options. For example, in Upper Austria, the majority of disabled people (approximately 70%) live in residential settings¹¹³. Despite the need for mainstream living arrangements and personal assistance, ESI Funds have been used to build segregated living facilities for disabled people. Six such facilities were built – some of them are extensions of existing large institutions, another links the residential setting to a sheltered workshop, creating a ‘total institution’, yet another replaces a smaller older facility (for 6 people) with larger one (for 16 people)¹¹⁴.

EU funding for personal assistance schemes

It is positive that money from the ESI Funds has been used by some EU Member States to support personal assistance schemes (for example in Bulgaria, Croatia, Cyprus and Portugal), allowing more disabled people to have access to the service. However, the organisation of the service has often not been in line with the requirements of the CRPD and General Comment 5 and has thus failed to adequately support independent living. For example, in Croatia, the number of hours of assistance was limited to only 20 per week and the service is not available to children or people above 65 (unless they have had access before). The lack of administrative capacity by the relevant ministry has also caused problems for implementing NGOs, which rely on project funding to guarantee the continuity of personal assistance. Some schemes in Bulgaria allowed only working-aged people to become assistants. Concerns have also been raised by the CRPD Committee about the sustainable provision of independent living services following the termination of ESI Funds¹¹⁵.

Limitations of EU policies and guidance to Member States

In 2014, the EC issued a draft thematic guidance on deinstitutionalisation for desk officers, responsible for overseeing EU funds, stating that ‘[b]uilding or renovating long-stay residential institutions is excluded, regardless of their size’¹¹⁶. However, in June 2018, the Legal Service opinion¹¹⁷, issued by the European Commission and addressed internally 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’

¹¹³ IL Austria and ENIL (2020) Complaint – Infringement of EU Law. Available at: https://enil.eu/wp-content/uploads/2020/07/Complaint_by_Independent_Living_Austria_ENIL.pdf.

¹¹⁴ IL Austria and ENIL (2021) Further information regarding the complaint submitted by the European Network on Independent Living and Independent Living Austria in July 2020, ref: CHAP(2020)1883.

¹¹⁵ Committee on the Rights of Persons with Disabilities (2017) Concluding observation on the initial report of Latvia, CRPD/C/LVA/CO/1. Available at: https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fLVA%2fCO%2f1&Lang=en, para. 31,b.

¹¹⁶ European Commission (2014) Draft thematic guidance fiche for desk officers on the transition from institutional to community-based care (de-institutionalisation).

¹¹⁷ European Commission Legal service, Ref. Ares(2018)3471732-29/06/2018.

and in cases of residential institutions ‘for persons requiring constant care and medical supervision’.

According to the 2015 thematic guidance for Member States on the use of ESIFs in tackling educational and spatial segregation, interventions addressing the needs of ‘marginalised communities’ must follow the principles of ‘non-segregation’ and ‘desegregation’. This means that ‘investments in housing or education should not lead to increased concentration or further physical isolation of marginalised groups’¹¹⁸. This guidance, however, has not been applied with regard to interventions related to disabled people, although its scope covers Roma and ‘other socially disadvantaged groups’.

The EU Strategy for the Rights of Persons with Disabilities 2021-2030 puts greater emphasis on independent living and demonstrates a commitment of the European Commission to end the practice of institutionalisation across EU Member States. ENIL welcomes the Commissions’ flagship initiative to issue guidance to Member States on improving independent living and inclusion in community’ by 2023. However, we are concerned that this initiative could sustain or expand the isolation of disabled people in group homes, if it does not explicitly recognise the segregating nature of group homes and emphasises the need to move away from such settings, encouraging the development of a range of community supports and services, such as personal assistance, and creating pathways to accessible and affordable housing.

Suggested questions for the LOIPR:

- What measures will the EU take to ensure that EU funds are used for the development of inclusive community services for disabled people, rather than invested in segregating services?
- What measures will the EU take to ensure that its guidance regarding the use of EU Funds is in line with the CRPD and General Comment 5 when it comes to institutions for disabled people, including group homes?
- How will the EU ensure that the planned guidance on improving independent living and inclusion in community will not contribute to re-institutionalisation and segregation of disabled people in small residential settings?
- What guidance will the EU provide to Member States to ensure that EU-funded personal assistance schemes are consistent with the CRPD and General Comment 5?
- Why has the EU not intervened to stop the investment of EU-money in small institutions for disabled people in countries other than Hungary (for example,

¹¹⁸ EC (2015) Guidance for Member States on the use of European Structural and Investment Funds in tackling educational and spatial segregation, p. 6. Available at: https://ec.europa.eu/regional_policy/sources/docgener/informat/2014/thematic_guidance_fiche_segregation_en.pdf.

Estonia and Bulgaria)?

- Does the EU plan to ratify the CRPD Optional Protocol?

Article 23 - Respect for home and the family

Continued institutionalisation of children with disabilities

The DataCare project recorded a total number of 302,979 children in residential care in the EU countries¹¹⁹. A disproportionate number of children with disabilities live in institutional and residential care¹²⁰. For example, in Flanders, the Flemish region of Belgium, 92% of children in institutional care are with disabilities¹²¹. In many countries, children with disabilities are much more likely to be placed in institutional care than those without disabilities¹²².

One of the key factors for the separation of children with disabilities from their families and their placement in residential care is the insufficient or lacking information and support for them and their families¹²³. Without adequate assistance, families are often unable to care for their child at home. Even where support services do exist, they are sometimes insufficient or unequally distributed - mainly concentrated in or around the cities, while access of people living in the countryside to services tends to be much more limited¹²⁴.

In some countries, children with disabilities can be forcibly taken away from their parents and placed in a residential setting. This is the case, for example, in France, where children with autism are institutionalised against the will of their parents. A report by the UN Special Rapporteur on the rights of persons with disabilities reported that 'some parents who oppose the institutionalization of their children with disabilities are intimidated and threatened and, in some cases, lose custody of their children, with the children being forcibly institutionalized or subject to administrative placement'¹²⁵.

While EU funding has been used to advance deinstitutionalisation of children in some Member States, a recent study concluded that 'national experts were asked to identify

¹¹⁹ Eurochild (2021) Children in alternative care: Comparable statistics to monitor progress on deinstitutionalisation across the European Union. Available at https://eurochild.org/uploads/2021/12/Children-in-alternative-care_Comparable-statistics-to-monitor-progress-on-DI-across-the-EU.pdf

¹²⁰ Lerch, V. and Severinsson, A. (2019). Target group discussion paper on children in alternative care. Brussels: European Commission. Available at: <https://op.europa.eu/en/publication-detail/-/publication/f8373a0f-c7dd-11ea-adf7-01aa75ed71a1/language-en>.

¹²¹ Opening Doors for Europe's Children (2018). Belgium. 2018 country fact sheet. Available at: <https://eurochild.org/uploads/2022/01/Opening-Doors-country-fiche-Belgium-2018.pdf>.

¹²² Crowther, N. (2019), *op. cit.*

¹²³ Lerch, V. and Severinsson, A., *op. cit.*

¹²⁴ Opening Doors for Europe's Children (2018). Romania. 2018 country fact sheet. Available at: <https://eurochild.org/uploads/2022/01/Opening-Doors-country-fiche-Romania-2018.pdf>.

¹²⁵ Report of the Special Rapporteur on the rights of persons with disabilities (2019). Available at <https://undocs.org/en/A/HRC/40/54/Add.1> p. 51

the extent to which EU Funds are already used at national level to ensure the rights of the TG [target group], but most noted that they had difficulty tracing information on how EU Funds were being used. There was mostly no further detailed information on how the money was spent, nor on whether the programmes had any direct or indirect impact on children¹²⁶.

Furthermore, despite policy initiatives promoting the rights of the child at EU level, the Council Recommendation (EU) 2021/1004 of 14 June 2021 establishing a European Child Guarantee still allows for placement of children in institutions. It states, in preamble 24, that: “Placing children in institutional care should be done only when it is in the best interests of the child, taking into account the child’s overall situation and considering the child’s individual needs.” In article 10, on Adequate housing, it recommends that Member States should “take into account the best interests of the child as well as the child’s overall situation and individual needs when placing children into institutional or foster care.”¹²⁷

Suggested questions for the LOIPR:

- How will the EU promote the development of policies and services supporting families and preventing separation and institutionalisation?
- What measures will the EU take to address the practice of institutionalisation of children with disabilities?

Article 24 - Education

Limited support in community and mainstream schools reinforces segregation

A large number of children with disabilities in Europe remain excluded from quality inclusive education. It has been estimated that at least 75% of children with disabilities in Central and Eastern Europe (CEE) and Central Asia are excluded from quality inclusive education¹²⁸.

The segregation of children in special settings is facilitated, among others, by the limited support in the mainstream education system and in the community. For example, in Ireland, parents are sometimes encouraged to send their children to special rather than mainstream schools in order to be able to access medical

¹²⁶ Directorate-General for Employment, Social Affairs and Inclusion (2019). Target Group Discussion Paper on Children in Alternative Care. Brussels. European Commission. p 42.

¹²⁷ COUNCIL RECOMMENDATION (EU) 2021/1004 of 14 June 2021. Establishing a European Child Guarantee. Available at: <https://eur-lex.europa.eu/legal-content/EN/TXT/HTML/?uri=CELEX:32021H1004&from=EN> and <https://deinstitutionalisation.com/newsflash/>.

¹²⁸ UNICEF (2019). 75% of children with disabilities in Eastern and Central Europe and Central Asia left out of inclusive, quality education. Available at: <https://www.unicef.org.uk/press-releases/75-of-children-with-disabilities-in-eastern-and-central-europe-and-central-asia-left-out-of-inclusive-quality-education-unicef/>.

support¹²⁹. In Luxembourg, specialised services, such as physiotherapy, occupational therapy and speech therapy are only provided in special schools, forcing some parents to choose special education for their children¹³⁰. In Malta, the limited support in mainstream schools is also a hindrance for young disabled people wishing to continue with their studies after completing their compulsory education¹³¹.

Suggested question for the LOIPR:

- What steps will the EU take to promote the provision of support in mainstream educational settings and in the community, allowing for inclusive education of children with disabilities?

Article 25 - Health

Denial of essential healthcare

Throughout Europe, disabled people have been subjected to unnecessary pain and suffering because of denied medical treatment. For example, in November 2021, members of a Romanian NGO found a 33-year-old, severely malnourished (20kg) woman in a nursing home for older persons. The woman had been subjected to 4 months of unnecessary pain and suffering, having been denied medical treatment for a fracture to her leg¹³².

Denial of healthcare during the COVID-19 pandemic

The COVID-19 pandemic exposed the systemic denial and rationing of healthcare for disabled people across the EU Member States. Guidelines sent to nursing homes by Madrid's department of health stated that people who cannot move independently, have intellectual disability, or have a comorbidity should not be sent to hospital¹³³. Reports from Italy suggested that doctors were rationing intensive care treatment based on who was 'deemed worthy of intensive care'¹³⁴.

¹²⁹ Independent Living Movement Ireland (2021) Observations on Ireland's first draft report to the UN under the Convention on the Rights of Persons with Disabilities. Available at: <https://ilmi.ie/wp-content/uploads/2021/04/ILMI-observations-on-Irelands-Report-to-the-UNCPRD.docx>

¹³⁰ Pancyprian Alliance for Disability (2019) Submission of the Pancyprian Alliance for Disability to the Committee on the Rights of the Child on the implementation of the Convention on the Rights of the Child with focus on Children with Disabilities, para.31. Available at: https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=INT%2fCRC%2fNGO%2fCYP%2f35881&Lang=en.

¹³¹ Carabott, S. (2020). Many children with a disability give up on their studies. *Times of Malta* 15 February 2020. Available at: <https://timesofmalta.com/articles/view/many-children-with-a-disability-give-up-on-their-studies.770951>.

¹³² Centrul de Resurse Juridice (2021). https://www.crj.ro/scrisoare-deschisa-georgiana-un-om-sau-doar-o-cifra/?fbclid=IwAR3zTdIPRYS7Uz6u3vVTxcbR3oy2ZUSmd2o10fJdNBIUv5H9dsVL17SF_QY

¹³³ Rada, A. G. (2020) Covid-19: the precarious position of Spain's nursing homes. *British Medical Journal* doi: 10.1136/bmj.m1554

¹³⁴ Lintern, S. (2020). 'We are making difficult choices': Italian doctor tells of struggle against coronavirus. Available at <https://www.independent.co.uk/news/health/coronavirus-italy-hospitals-doctor-lockdown-quarantine-intensive-care-a9401186.html>.

Suggested question for the LOIPR:

- How will the EU ensure that disabled citizens are not denied the right to healthcare?

Article 27 - Work and employment

Disabled people disproportionately exposed to unemployment and job insecurity

Figures obtained by the EU show that the employment rate of disabled people (aged 20-64) stands at 50.8%, compared to 75% for the general population¹³⁵. In addition, disabled people in employment are more likely to receive temporary contracts, lower wages and are more likely to lose their jobs in economic recessions¹³⁶. This means that disabled people have less access to employment-based social security, making them particularly at risk of poverty¹³⁷.

A recent proposal for a Directive on adequate minimum wages in the European Union recognised that disabled people 'have a higher probability of being minimum wage or low wage earners than other groups. During economic downturns, such as the Covid-19 crisis, the role of minimum wages in protecting low-wage workers becomes increasingly important and is essential to support a sustainable and inclusive economic recovery'¹³⁸. This Directive that protects the minimum wage for workers is particularly important for disabled citizens, who have been targeted by governments wanting to cut minimum wage. For example, the government of the Netherlands proposed legislation that would have allowed employers to ask disabled employees to take a 'productivity test' which would have allowed employers to pay disabled workers less than the minimum wage¹³⁹.

Denial of employment rights in EU funded sheltered workshops

In addition to the essential minimum wage directive, the EU must also act on behalf of the significant number of disabled people who are denied employment rights in sheltered employment. The European Strategy for Persons with Disabilities 2021-2030 recognises that 'large number of persons with severe disabilities do not work in the

¹³⁵ A New Ambitions Disability Strategy for 2021-2030. Available at <https://www.europarl.europa.eu/news/en/headlines/society/20200604STO80506/a-new-ambitious-eu-disability-strategy-for-2021-2030>.

¹³⁶ European Foundation Centre (2012). Assessing the impact of European government's austerity plans on the rights of people with disabilities. Available at <https://www.eesc.europa.eu/sites/default/files/resources/docs/austerity2012.pdf>

¹³⁷ Rotarou, E. S., Sakellariou, D., Kakoullis, E. J., & Warren, N. (2021). Disabled people in the time of COVID-19: identifying needs, promoting inclusivity. *Journal of global health*, 11.

¹³⁸ European Commission (2020). Proposal for a Directive of the European Parliament and of the Council on adequate minimum wages in the European Union Available at <https://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=CELEX:52020PC0682&from=EN>.

¹³⁹ Dijkhof, F. (2018). Netherlands: Society's Dignity Going down the Drain? Available at <https://enil.eu/news/netherlands-societys-dignity-going-down-the-drain/>

open labour market, but in facilities offering so-called sheltered employment¹⁴⁰. Despite this, EU funding continues to support the construction of sheltered workshops that deny disabled people employment rights. €7.5 million of the European Agricultural Fund for Rural Development (EAFRD) have been used in Upper Austria to build institutions and sheltered employment facilities for disabled people¹⁴¹. A report by the Director-General for Internal Policies at the European Parliament recognised that disabled people in sheltered employment in Austria are denied employment protection laws and are denied access to independent social security¹⁴². A complaint filed to the European Commission found that the ‘projects co-financed by EAFRD have... reinforced the segregation, isolation and discrimination of persons with disabilities in Upper Austria’¹⁴³. EU investment in sheltered workshop violates the Council Directive 2000/78/EC on equal treatment in employment and occupation, which stresses ‘the need to foster a labour market favourable to social integration by formulating a coherent set of policies aimed at combating discrimination against groups such as persons with disability’¹⁴⁴. Despite this, the EU has failed to take any concrete action, for example by sanctioning the use of EU funding or providing guidance to Member States.

European Solidarity Corps promoting employment and volunteering in institutions

The European Solidarity Corps is an EU initiative to support youth employment across the EU. Jobs and volunteering opportunities included under ‘disability inclusion’ include an institution which houses 40 disabled people¹⁴⁵, a boarding school for 54 disabled children¹⁴⁶ and another boarding school for more than 200 disabled children¹⁴⁷. These placements support the maintenance of institutions in Europe. Furthermore, voluntary work in an institution is misrepresented as ‘disability inclusion’.

Suggested questions for the LOIPR:

- What measures will the EU take to protect disabled workers against precarious employment?

¹⁴⁰ A new ambitious EU Disability Strategy for 2021-2030 Available at

<https://www.europarl.europa.eu/news/en/headlines/society/20200604STO80506/a-new-ambitious-eu-disability-strategy-for-2021-2030>.

¹⁴¹ European Network on Independent Living (2020). EU Structural Funds Used to Segregate Disabled People in Austria. Available at <https://enil.eu/news/press-release-eu-structural-funds-used-to-segregate-disabled-people-in-austria/>

¹⁴² A New Ambitions Disability Strategy for 2021-2013. Available at https://www.europarl.europa.eu/RegData/etudes/STUD/2015/536295/IPOL_STU%282015%29536295_EN.pdf p. 23.

¹⁴³ Complaint – Infringement of EU law (2020). Available at https://enil.eu/wp-content/uploads/2020/07/Complaint_by_Independent_Living_Austria_ENIL.pdf

¹⁴⁴ Council Directive 2000/78/EC Available at <https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=celex%3A32000L0078>

¹⁴⁵ https://europa.eu/youth/volunteering/organisation/48972_en

¹⁴⁶ https://europa.eu/youth/volunteering/organisation/50893_en

¹⁴⁷ European Youth Portal (2022). Available at https://europa.eu/youth/volunteering/organisation/62309_en

- What measures will the EU take to ensure that EU funds are not misused to build sheltered employment that denies disabled people their employment rights?
- What measures will the EU take to ensure that the European Solidarity Corps does not support employment and volunteering in institutions?

Article 28 - Adequate standard of living and social protection

Disproportionate impact of austerity on disabled people

The COVID-19 pandemic has accelerated poverty among disabled people. The rising cost of living, inflation, and housing crises, together with a breakdown of supports and services resulted in disabled people not being able to afford essentials, including food and medication¹⁴⁸. The pandemic follows more than a decade of austerity measures required by the International Monetary Fund (IMF), the European Commission and the European Central Bank. The austerity measures required by the IMF, European Commission and the European Central Bank are a clear example of how European policy places disabled citizens at greater risk of poverty. These austerity measures have had a devastating and disproportionate impact on disabled people. For instance, the Irish government reduced disability allowance and the drug payment scheme which subsidises additional medical costs. Austerity measures remained in place for disabled people, despite Ireland's exit from the Troika¹⁴⁹ in 2014¹⁵⁰. Austerity measures were misused to justify cutbacks to supports and services that enable disabled people to live independently in the community. In the case of the United Kingdom, the UN Committee on the Rights of Persons with Disabilities recognised that use of austerity measures led to grave and systematic human rights violations¹⁵¹.

Suggested question for the LOIPR:

- How will the EU ensure that disabled people are not disproportionately impacted by austerity measures?

¹⁴⁸ COVID-19 Disability Rights Monitor (2020) Available at <https://www.covid-drm.org/en/statements/covid-19-disability-rights-monitor-calls-on-governments-to-ensure-access-to-food-medication-and-essential-supplies-for-persons-with-disabilities>

¹⁴⁹ The Troika was made up of the European Commission (EC), the European Central Bank (ECB) and the International Monetary Fund (IMF) to oversee austerity measures.

¹⁵⁰ O'Sullivan, C., & McNamara, D. (2021). The 'Necessity' of Austerity and its Relationship with the UN Convention on the Rights of Persons with Disabilities: A Case Study of Ireland and the United Kingdom. *Human Rights Law Review*, 21(1), 157-185.

¹⁵¹ Committee on the Rights of Persons with Disabilities (2017). Inquiry concerning the United Kingdom of Great Britain and Northern Ireland carried out by the Committee under article 6 of the Optional Protocol to the Convention Available at https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2f15%2f4&Lang=en

Article 32 - International cooperation

Lack of support to deinstitutionalisation reforms outside EU

ENIL, in cooperation with the European Disability Forum, carried out research into the use of EU external action funding (i.e. its development and humanitarian aid) for the purpose of supporting deinstitutionalisation reforms¹⁵². As the world's largest donor and the only regional organisation to have ratified the CRPD, the EU is in a strong position to provide leadership on this issue and to facilitate better access to the right to live independently and being included in the community. This is especially so during the process of EU enlargement.

In consultation with DPOs from countries benefitting from EU funding, we have identified the following key concerns: a) there is a lack of projects on deinstitutionalisation funded by the EU; b) deinstitutionalisation is understood as moving residents from large to small institutions; c) there is a lack of clear criteria (which would ensure compliance with the CRPD) for the selection of projects; d) contracts are awarded to beneficiaries with the lack of expertise on deinstitutionalisation; e) there is a lack of sustainability of the newly-developed services, as a result of which people might lose support once the funding ends; f) it is extremely difficult, if not impossible, to access comprehensive information about the projects funded; and g) there is a lack of involvement of DPOs in programming, implementation and monitoring of EU funds globally. Finally, we have found that EU's reliance on international organisations, including UN agencies, to implement the projects excludes DPOs from decisions and processes which concern them.

Suggested question:

- What measures is the EU taking to ensure that the EU external action funding only supports projects compliant with the CRPD, and does not reinforce the segregation of disabled people in large or small institutions?

Article 33 - Implementation and monitoring

Inadequate investigation of alleged human rights violations

In 2020, ENIL and its members submitted complaints to the European Commission concerning the segregation and social exclusion of disabled people in institutions funded by the European Regional Development Fund (ERDF) in Romania and Estonia¹⁵³. The European Commission responded almost one year after the complaint

¹⁵² Bulic Cojocariu, Ines (2022) Role of the European Union funding in supporting deinstitutionalisation around the world: A Call for Change, European Disability Forum and European Network on Independent Living. Available at: https://enil.eu/wp-content/uploads/2022/02/ENILEDf_DI-Global-Report_Final_forPublication_140222.pdf

¹⁵³ European Network on Independent Living (2020). Complaint – Infringement of EU law. Available at https://enil.eu/wp-content/uploads/2020/12/Romania_Complaint_ESIF_131219_FIN.pdf

was made. The Commission claimed that the investments are not violating EU law¹⁵⁴. Their response stated that there is no 'general and absolute prohibition to support long-stay residential institutions'¹⁵⁵. The response from the Commission also stated that Member States are responsible for the drawing up of the programmes and selecting the projects which will be co-financed by the ESI Funds. It is up to Member States to set up the operations they would like to co-finance in the context of the process to ensure independent living arrangements and deinstitutionalisation'¹⁵⁶.

The Commission's examination of the complaints was limited to a paper-based assessment of strategies, plans and other documents provided by the Managing Authorities in the two countries¹⁵⁷. Romanian authorities have consistently denied the use of torture and physical restraints in institutions, despite video evidence of torture including children tied to beds, tied to door handles and placed in solitary confinement^{158 159}. These institutions used ESI Funds for their so-called de-institutionalisation programmes.

Inadequate complaints mechanism

The European Commission has introduced a complaints system for breaches of EU law¹⁶⁰, which ENIL has used to file complaints against the Managing Authorities in EU Member States using ESI Funds to build or renovate institutions for disabled people. We have filed several complaints in relation to Romania, Poland and Austria, mostly in cooperation with our members from these countries. In addition to this system, we have used other avenues (i.e. contacting the relevant Commission services) to file complaints against Hungary, Bulgaria, Portugal and Estonia, among other.

To this date, despite the strong legal basis provided by EU's and the Member States' ratification of the CRPD, the European Commission has not found a single breach of EU law in response to our complaints and has relied on its Legal opinion from 2018 to justify investments in institutions for disabled people. All decisions regarding our complaints have consistently interpreted the CRPD and the General Comment 5 as allowing investments in institutions.

In addition to using the Commission's complaints system, ENIL and our members have filed a petition against Bulgaria to the Petitions Committee at the European Parliament (Petition no. 0862/2018) and a complaint against the European Commission for allowing investments into institutions in Hungary and Portugal to the European

¹⁵⁴ Ibid

¹⁵⁵ European Commission (2020) Response Available at https://validity.ngo/wp-content/uploads/2020/12/CHAP20193555_Pre-closer-Letter_181120.docx.pdf

¹⁵⁶ Ibid

¹⁵⁷ Ibid

¹⁵⁸ Spiller, S (2013). People & Power - Europe Hidden Shame. Al Jazeera. Available at <https://www.youtube.com/watch?v=obXewZYWLeY&t=1212s>.

¹⁵⁹ European Network on Independent Living (2015). Child Abuse Raises Questions Over Effectiveness of Deinstitutionalisation Programme In Romania. Available at <https://enil.eu/news/child-abuse-raises-questions-over-effectiveness-of-deinstitutionalisation-programme-in-romania/>

¹⁶⁰ See: https://ec.europa.eu/assets/sg/report-a-breach/complaints_en/index.html.

Ombudsman (Case 1233/2019)¹⁶¹. Furthermore, we have taken a case to the General Court in Luxembourg (Case T-613/19), challenging the Commission's lack of action to stop EU funds investments in institutions in Bulgaria. The case was dismissed on procedural grounds.

Inadequate EU response to human rights violations

Following the CRPD Committee inquiry report on Hungary, which criticised the re-institutionalisation of disabled people in EU-funded 'supported housing' (project EFOP-2.2.2-17), the European Commission intervened and stopped the continuation of this process (project EFOP-2.2.5-17), raising concern about the housing model¹⁶². However, the Commission has failed to apply its recommendations for Hungary to other countries with similar practices, despite the numerous complaints submitted by ENIL and its members (as listed above). We have been unable to bring our complaints directly to the CRPD Committee, as the EU has not yet ratified the CRPD Optional Protocol.

Suggested questions for the LOIPR:

- What concrete measures will the EU take to investigate accusations of human rights abuses?
- What measures will the EU take to ensure that its complaint mechanism for breaches of EU law involves adequate investigation, which is not limited to review of submitted by the government documents, but also includes independent assessment (for example, by national human rights institutions)?

¹⁶¹ See: <https://www.ombudsman.europa.eu/en/decision/en/130886>

¹⁶² European Ombudsman (2020). Decision in case 1233/2019/MMO on how the European Commission ensures that Member State governments spend European Structural and Investment Funds in line with the obligations stemming from the United Nations Convention on the Rights of Persons with Disabilities. Available at: https://www.ombudsman.europa.eu/en/decision/en/130886#_ftnref13

Appendix 1: The list of Concluding Observations on the initial report of the European Union relevant to this report

Article 5 Equality and non-discrimination

The Committee recommends that the European Union adopt its proposed horizontal directive on equal treatment, extending protection against discrimination to persons with disabilities, including by the provision of reasonable accommodation in all areas of competence. The Committee also recommends that the European Union ensure that discrimination in all aspects on the grounds of disability is prohibited, including multiple and intersectional discrimination.

Article 7 Children with Disabilities

23. The Committee recommends that the European Union take the necessary measures, including through the use of the European Structural and Investment Funds and other relevant European Union funds, to develop support services for boys and girls with disabilities and their families in local communities, foster deinstitutionalization, prevent any new institutionalization and promote social inclusion and access to mainstream, inclusive, quality education for boys and girls with disabilities. The Committee also recommends that the renewed Agenda for the Rights of the Child include a comprehensive rights-based strategy for boys and girls with disabilities and safeguards to protect their rights. The Committee further recommends that all disability strategies address and mainstream the rights of boys and girls with disabilities.

Article 11 Situations of Risk and Humanitarian Emergencies

33. The Committee recommends that the European Union: (a) adopt an implementation plan in line with the Council conclusions on disability-inclusive disaster management of February 2015 and the Sendai Framework for Disaster Risk Reduction 2015-2030; (b) establish a mechanism to build capacity and share good practices among the different European Union institutions and among its Member States on disability-inclusive and accessible humanitarian aid; (c) establish a monitoring and accountability framework for the implementation of European Union policies and programmes, including the collection of data disaggregated by sex, disability and age.

Article 12 Equal recognition before the law

37. The Committee recommends that the European Union take appropriate measures to ensure that all persons with disabilities who have been deprived of their legal capacity can exercise all the rights enshrined in European Union treaties and legislation, such as access to justice, goods and services, including banking, employment and health care, as well as voting and consumer rights, in line with the Convention, as developed in the Committee's general comment No. 1 (2014) on equal recognition before the law. The Committee also recommends that the European Union step up efforts to foster research, data collection and exchange of good practices on

supported decision-making, in consultation with representative organizations of persons with disabilities.

Article 14 Liberty and security of persons

The UN Committee on the Rights of Persons with Disabilities expressed concern ‘about the involuntary detention of persons with disabilities in psychiatric hospitals or other institutions on the basis of actual or perceived impairment’.

Article 18 Freedom of Movement

49. The Committee recommends that the European Union take immediate action to ensure that all persons with disabilities and their families can enjoy their right to freedom of movement on an equal basis with others, including with regard to the portability of social security benefits, in a coordinated manner across its Member States.

Article 19 Living independently and being included in the community

51. The Committee recommends that the European Union develop an approach to guide and foster deinstitutionalization and to strengthen the monitoring of the use of the European Structural and Investment Funds so as to ensure that they are used strictly for the development of support services for persons with disabilities in local communities and not for the redevelopment or expansion of institutions. The Committee also recommends that the European Union suspend, withdraw and recover payments if the obligation to respect fundamental rights is breached.

Article 23 Respect for Home and the Family

57. The Committee recommends that the European Union take appropriate measures to ensure that its economic and social policies and recommendations promote support for families with persons with disabilities and ensure the right of children with disabilities to live in their communities.

Article 24 Education

61. The Committee recommends that the European Union evaluate the current situation and take measures to facilitate access to and enjoyment of inclusive, quality education for all students with disabilities in line with the Convention and include disability-specific indicators in the Europe 2020 strategy when pursuing the education target.

Article 25 Health

63. The Committee recommends that the European Union explicitly prohibit discrimination on the grounds of disability in the field of health care and take measures to ensure access to quality health care for all persons with all types of disabilities. It also recommends that the European Union evaluate the impact of the European Parliament and the Council of the European Union Directive 2011/24/EU on patients’ rights in cross-border health care with regard to gaps in access for persons with disabilities, including accessible information, reasonable accommodation and training

of professionals’.

Article 27 Work and Employment

The Committee recommends that the European Union take effective action to measure the employment of persons with disabilities and to increase their employment CRPD/C/EU/CO/1 9 rate in the open labour market, including by providing training for Member States on reasonable accommodation and accessibility in the context of employment.

Article 28 Adequate standard of living and social protection

67. The Committee recommends that the European Union take urgent measures, in cooperation with its Member States and representative organizations of persons with disabilities, to prevent further adverse and retrogressive effects of the austerity measures on the adequate standard of living of persons with disabilities, including by setting a social protection floor that respects the core content of the right to an adequate standard of living and to social protection.

Appendix 2: Explanation of EU competencies by CRPD article, as relevant to this report

Article 5 Equality and non-discrimination

Article 21 of the Charter of Fundamental Rights prohibits discrimination on multiple grounds, including disability.

Article 7 Children with Disabilities

Article 3(3) of the Treaty on European Union establishes the objective for the EU to promote protection of the rights of the child. Article 24 of the Charter of Fundamental Rights of the EU states that ‘children shall have the right to such protection and care as is necessary for their well-being’

Article 10 Right to Life

Article 2 of the European Charter of Fundamental Rights protects the Right to life of European Union citizens. Likewise, Article 2 of the European Convention on Human Rights protects the Right to Life. In the case of *Jasinskis v. Latvia*, the European Court of Human Rights reiterated that ‘Article 2 of the Convention not only required a State to not “intentionally” take a life, but also to take appropriate steps to safeguard the lives of those within its jurisdictions’¹⁶³.

Article 11 Situations of Risk and Humanitarian Emergencies

The European Commission is a signatory to the Sendai Framework for Disaster Risk-Reduction. The Commission says it is at ‘the forefront of promoting risk reduction and anticipatory actions and ‘supports the adoption of a risk-informed approach into all EU policies and programmes’¹⁶⁴. The European Commission has also endorsed the Charter on Inclusion of Persons with Disabilities in Humanitarian Action (2016) which recognises that ‘persons with disabilities and their representative organizations have untapped capacity and are not sufficiently consulted nor actively involved in decision-making processes concerning their lives, including in crisis preparedness and response coordination mechanisms’¹⁶⁵. The Eurocodes outline mandatory building standards for EU Member States¹⁶⁶.

Article 14 Liberty and security of persons Article 6 of the EU Charter of Fundamental Rights ensures that ‘everyone has the right to liberty and security of person’. Article 5 of the European Convention on Human Rights protects the right to

¹⁶³ European Court of Human Rights. (2022) Persons with disabilities and the European Convention on Human Rights Available at https://echr.coe.int/Documents/FS_Disabled_ENG.pdf p.1

¹⁶⁴ European Civil Protection and Humanitarian Aid Operations. Disaster Preparedness. Available at https://ec.europa.eu/echo/what/humanitarian-aid/disaster-preparedness_en

¹⁶⁵ Charter of inclusion of persons with disabilities in humanitarian action. (2016). Available at <http://humanitariandisabilitycharter.org/>

¹⁶⁶ Eurocodes Available at: <https://eurocodes.jrc.ec.europa.eu/showpage.php?id=1>

liberty and security. In the case of *Stanev v. Bulgaria*, the Grand Chamber of the European Court of Human Rights held that there had been a violation of the right to liberty and security, in that the applicant had been illegally detained in a social care home against his will¹⁶⁷.

Article 15 Freedom from torture or cruel, inhuman, or degrading treatment or punishment

Article 4 of the EU Charter of Fundamental Rights states that ‘no one shall be subjected to torture or to inhuman or degrading treatment or punishment.’ Likewise, Article 3 of the European Convention on Human Rights ensures that ‘no one shall be subjected to torture or to inhuman or degrading treatment or punishment’. In the case of *Aggerholm vs. Denmark* (2020) the European Court of Human Rights ‘held that there had been a violation of Article 3 (prohibition of inhuman and degrading treatment) of the Convention, finding that the Danish authorities had not sufficiently proven that continuing to strap the applicant to a restraint bed for 23 hours had been strictly necessary’¹⁶⁸.

Article 18 Freedom of movement

The freedom of movement of EU citizens is established by Article 3(2) of the Treaty on European Union, Article 21 of the Treaty on the Functioning of the European Union and Article 45 of the Charter of Fundamental Rights of the European Union.

Article 19 Living independently and being included in the community

Article 26 of the Charter of Fundamental Rights of the European Union states that the ‘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.’

The EC Strategy for the Rights of Persons with Disabilities 2021 – 2030 identifies “developing independent living and reinforcing community-based services” as one of the three priorities for the EU. It promises that the “Commission will support national, regional and local authorities in their efforts for deinstitutionalisation and independent living, including through the 2021 – 2027 shared management funds”.

Section 13 of Regulation (EU) No 1303/2013 of the European Parliament and of the Council states that ‘the Union should, at all stages of implementation of the ESI Funds, aim at eliminating inequalities and at promoting equality between men and women and integrating the gender perspective, as well as at combating discrimination based on sex, racial or ethnic origin, religion or belief, disability, age or sexual orientation.

¹⁶⁷ European Court of Human Rights. (2022) Persons with disabilities and the European Convention on Human Rights Available at https://echr.coe.int/Documents/FS_Disabled_ENG.pdf

¹⁶⁸ European Court of Human Rights. (2022) Persons with disabilities and the European Convention on Human Rights. Available at https://echr.coe.int/Documents/FS_Disabled_ENG.pdf

The EU Declaration of Competences¹⁶⁹ and its updated version establishes direct link between the regulations governing ESI Funds and the UN CRPD¹⁷⁰.

Article 23 Respect for Home and the Family

Article 7 of the European Charter for Fundamental Rights says that ‘everyone has the right to respect for his or her private and family life, home and communications’. Likewise, Article 8 of the European Convention on Human Rights states that ‘everyone has the right to respect for his private and family life, his home and his correspondence’.

Article 25 Health

Article 35 of the EU Charter of Fundamental Rights ensures that ‘everyone has the right of access to preventive health care and the right to benefit from medical treatment under the conditions established by national laws and practices. A high level of human health protection shall be ensured in the definition and implementation of all Union policies and activities.’

Article 27 Work and Employment

Council Directive 2000/78/EC on the equal treatment in employment and occupation protects persons with disabilities from discriminations and requires that reasonable accommodation is provided to enable persons with disabilities to “have access to, participate in, or advance in employment” (Article 5). The European Pillar of Social Rights, on inclusion of persons with disabilities recognises the right of persons with disabilities to “services that enable them to participate in the labour market and in society, and a work environment adapted to their needs”.

Article 28 Adequate standard of living and social protection

Combating poverty, social exclusion and discrimination are specific social policy goals of the EU and its MS¹⁷¹. The European Pillar of Social Rights Action Plan aims to reduce the number of EU citizens at risk of poverty or social exclusion by at least 15 million by 2030¹⁷².

¹⁶⁹ Council of the EU (2009). Council decision of 26 November 2009 concerning the conclusion, by the European Community, of the United Nations Convention on the Rights of Persons with Disabilities, 2010/48/EC. See: <https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX%3A32010D0048>.

¹⁷⁰ See also Quinn, G., de Búrca, G., Bell, M., Lawson, A., Stein, M, Mattsson, T., and Clements, L. (2018). Legal memo Segregation and segregated facilities as a prima facie form of discrimination. The Impermissibility of using the ESIF to invest monies in long term care residential institutions for persons with disabilities. See: <http://enil.eu/wp-content/uploads/2018/03/ESIF-Legal-Memo-final-edit.docx>.

¹⁷¹ The Right Against Poverty, Social Exclusion and Discrimination. Available at <https://www.europarl.europa.eu/factsheets/en/sheet/60/the-fight-against-poverty-social-exclusion-and-discrimination>

¹⁷² European Commission (2021). Communication from the Commission to the European Parliament, the Council, The European Economic and Social Committee and the Committee of the Regions Available at <https://eur-lex.europa.eu/legal-content/EN/TXT/HTML/?uri=CELEX:52021DC0102&from=EN>