# **Submission by the European Network on Independent Living on support systems for disabled people**

This submission brings together information compiled by the European Network on Independent Living (ENIL) for the OHCHR annual thematic study on the rights of persons with disabilities and support systems to ensure community inclusion of persons with disabilities requested by Human Rights Council resolution 49/12 ([A/HRC/RES/49/12](https://undocs.org/Home/Mobile?FinalSymbol=A%2FHRC%2F49%2F12&Language=E&DeviceType=Desktop&LangRequested=False)).

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. ENIL has special consultative status with ECOSOC and is a member of the of the Conference of INGOs of the Council of Europe. For more information, please see: [www.enil.eu](http://www.enil.eu).

**1(a). Does your country have laws, policies, plans, strategies or programmes at any level of government relating to individualized support for persons with disabilities?**

[The European Strategy for the Rights of Persons with Disabilities (ESRPD)](https://ec.europa.eu/social/main.jsp?catId=1484) is the document guiding disability policy of the European Union for the period 2021-2030. The ESRPD has ten chapters: 1. Vision and need for Action, 2. Accessibility – an enabler of rights, autonomy and equality, 3. Enjoying EU Rights, 4. Decent quality of life and living independently, 5. Equal Access and non-discrimination, 6. Promoting the rights of persons with disabilities globally, 7. Efficiently delivering the strategy, 8. Leading by example, 9. Awareness, governance and measuring progress, 10. Conclusion.

From and Independent Living point of view, Chapter 4 on “Decent quality of life and living independently” and especially chapter 4.1 on “Developing independent living and reinforcing community-based services” are key. In it, the European Commission announces plans to “by 2023 issue guidance recommending to Member States improvements on independent living and inclusion in the community in order to enable persons with disabilities to live in accessible, supported housing in the community, or to continue living at home (including personal assistance schemes).” To improve service delivery for persons with disabilities, the European Commission intends to “present, by 2024, a specific framework for Social Services of Excellence for persons with disabilities”.

[Part I of the ENIL survey on Independent Living](https://enil.eu/wp-content/uploads/2022/03/IL-Survey_Summary-report_Dec2020.pdf) in the Council of Europe area, which was published in 2020, revealed that 18 out of 43 countries have adopted deinstitutionalisation strategies (DI strategy). Among EU member states, 13 out of 27 countries have introduced deinstitutionalisation strategies: Bulgaria, Croatia, Cyprus, Estonia, Finland, Hungary, Ireland, Latvia, Lithuania, Poland, Romania, Slovakia and Slovenia. Out of 18 countries which have a deinstitutionalisation strategy, only one country, Moldova, has one that is considered adequate by the respondents. The 17 remaining strategies are evaluated as inadequate or requiring improvement. Recent information showed that the plan of action for deinstitutionalisation adopted by Poland in 2020 should be seen as inadequate. Documents adopted by governments as DI strategies are often overly complex and leave the reader without a clear idea on how deinstitutionalisation will unfold in the country. The DI strategies adopted by [Lithuania](https://socmin.lrv.lt/uploads/socmin/documents/files/pdf/9950_a1-83order.pdf) and [Poland](https://www.gov.pl/attachment/5b763e48-a84a-45a4-877c-727f051b23d8) are illustrative of the problem.

Noticeably absent from the list of EU countries that have a DI strategy, is the entirety of south-west Europe. None of the most populated EU members, France, Italy, Spain and Germany has adopted such a document.

The [ENIL independent living survey from 2020](https://enil.eu/wp-content/uploads/2022/03/IL-Survey_Summary-report_Dec2020.pdf) also revealed that 33 out of 43 countries in the Council of Europe area have personal assistance schemes in place. Within the EU, Luxembourg and Hungary do not have PA-schemes. Respondents evaluated the overwhelming majority of PA-schemes as “requiring improvement” or “inadequate”. Out of the 33 countries that have some form of personal assistance, only Slovenia was viewed as having adequate personal assistance. However, some sources also evaluate Slovenia´s PA-schemes as inadequate due to the limited number of hours granted to PA users.

**1(b). What are the government institutions, departments and ministries in charge of budgeting, financing and implementing the above?**

The European Commission is responsible for the implementation of the European Strategy on the Rights of Persons with Disabilities. Within the cabinet of Commissioners, Helena Dalli (Equality) and Nicolas Schmit (Jobs and Social Rights) are in charge of the different aspects of the ESRPD. On the administrative level, the Directorate General for Employment and Social Affairs (DG EMPL) is in charge of disability issues. The European Parliament and the Council of the EU are the legislative institutions. Within the European Parliament, the Committee on Employment and Social Affairs is responsible for disability issues. In the Council of the EU, national government representatives from the ministries responsible meet as the Council for Employment, Social Policy, Health and Consumer Affairs (EPSCO).

**1(c). How is the social and solidarity economy (third sector, non-profit sector), particularly the disability sector, involved in budgeting, financing and implementing the above (1(a))?**

The involvement of the third sector in the disability sector varies immensely between European countries.

**1(d). How are persons with disabilities and their representative organizations involved in the design and monitoring of the above (1(a))?**

At the EU level, the European Commission [financially supports](https://ec.europa.eu/info/funding-tenders/opportunities/portal/screen/opportunities/topic-details/cerv-2021-disa-og-sga) a number of EU level disability networks. Most organisations also take part in the work of the [Disability Platform](https://ec.europa.eu/social/main.jsp?langId=en&catId=1138&furtherNews=yes&newsId=10124), composed of the Member State representatives and the civil society, which takes part in monitoring of the ESRPD. Examples for representative organisations of disabled people involved are the following: European Network on Independent Living, ENIL; European Disability Forum; International Federation for Spina Bifida and Hydrocephalus; European Blind Union; European Union of the Deaf; Autism Europe and Inclusion Europe. DPOs can propose agenda points for the meetings of the Disability Platform, but most of the time is spent on updates from the European Commission policy departments and information shared by the Member States.

The European Commission also organises Strategic Dialogues with NGOs on the upcoming policies, where input can be submitted in writing and orally. However, no feedback is received as to why suggestions were rejected, or accepted. Also, the European Commission does not distinguish between DPOs and service providers – all are considered and claim to represent persons with disabilities. Therefore, we could say that involvement of representative organisations is partial and not entirely satisfactory. Also, DPOs have had no voice, for example, in the process leading up to the adoption of [EU Care Strategy](https://ec.europa.eu/info/law/better-regulation/have-your-say/initiatives/13298-European-care-strategy_en), which does not appear to be in line with the UNCRPD.

Involvement in the monitoring is superficial, only through the Disability Platform, as DPOs have no official role in monitoring of the ESRPD. The European Disability Forum is part of the [independent monitoring framework at EU level](https://fra.europa.eu/en/cooperation/eu-partners/eu-crpd-framework/monitoring), but the framework has no funding and is not effective.

At the level of the Council of Europe, there are no consultations open to NGOs when it comes to, for example, deinstitutionalisation, children, or the rights of persons with disabilities in general. ENIL is part of the conference of INGOs (meaning it has consultative status), but there is nothing relevant to persons with disabilities where we are invited to comment or take part in (meetings, conferences, consultations etc.).

**2(a). Does your country have legislation or policies, at any level of government, regulating and coordinating a care and support system that considers the areas mentioned in 1(a) above? Please provide references to the documentation**

The European Union currently has no deinstitutionalisation strategy, or policies personal assistance or other community-based services in place. Such strategies and systems are the responsibility of the national governments (Member States). As stated above, the European Commission plans to adopt guidelines on independent living and standards for ‘social services of excellence’ in the coming years.

**2(b). If yes, please describe how the care and support system is financed and what is the percentage of the eligible population covered.**

This question is not relevant to the European level, although the European Union funds, especially through the European Social Fund ‘care and support systems’ in a number of Member States. ENIL has [raised concerns over a number of years](https://enil.eu/funding/), and made complaints, about the misuse of EU funds for the building and renovation of institutions for persons with disabilities. Such practice continues to date in many Member States, without any action being taken by the EU institutions to stop it.

**3. Does your country have a strategy to develop legislation, policies and programmes to enable the development of support systems as described in 1(a) above which includes targets, indicators and an accountability mechanism? Please provide references to the documentation.**

The European Strategy on the Rights of Persons with Disabilities is the strategy that is supposed to the implementation of legislation, policies and programmes. The content of the strategy was explained earlier.

**4.**  **Please provide data on persons with disabilities and families and households accessing care and support systems as described above in 1(a) and 2(a).**

In 2007, the study [“Deinstitutionalisation and community living – outcomes and costs”](https://research.kent.ac.uk/tizard/2019/06/11/deinstitutionalisation-and-community-living-outcomes-and-costs/) found evidence of at least 1,294,253 disabled children and adults living in institutions throughout the EU. In 2020, the “[Report on the transition from institutional to community-based care](https://deinstitutionalisationdotcom.files.wordpress.com/2020/05/eeg-di-report-2020-1.pdf)” calculated that there were at least 1,438,696 disabled children and adults living in institutions. The [ENIL shadow report on the implementation of the UNCRPD](https://enil.eu/wp-content/uploads/2022/03/ShadowReport_EU_Final_140222.pdf), published in February 2022, gathered extensive evidence of a trend to replace large institutions with smaller residential settings in many member states. Such small-scale institutions are often called group homes. In these settings, the autonomy and self-determination of disabled people is curtailed in the same way as in larger institutions. As a result, the proliferation of group homes does not represent any progress towards deinstitutionalisation.

At the moment, there is no data on the number of persons benefiting from access to Personal Assistance in the EU.

**5. Please provide data on the impact of the COVID19 pandemic on persons with disabilities and families and households with members with disabilities (death rates disaggregated by disability status, death rates in institutions compared to those living in the community, impact on income as a consequence of disruption in support or increased support and care demands, disruption in support services, among other).**

*Source of information:* [ENIL Shadow report on the implementation of the UNCRPD](https://enil.eu/wp-content/uploads/2022/06/ENIL-UNCRPD-shadow-report.docx) (February 2022)

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 Europe. 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. For example, deaths in nursing homes account for 51% of the total COVID-19 deaths in the Netherlands[[1]](#footnote-1) and 68% of COVID related deaths in Spain..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 collected.

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 sanitation[[2]](#footnote-2).

The human rights violations recorded during the COVID-19 pandemic, although significant, are not an isolated incident[[3]](#footnote-3). Disabled people confined to institutions are inherently exposed to natural disasters, hazards, and infectious diseases[[4]](#footnote-4) 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).

Nursing homes have been criticised for locking doors in the name of ‘safety’. A Spanish study estimated that 85% of residents in Spanish nursing homes had been physically restrained. Deprivation of liberty intensified during the COVID-19 pandemic, with reports that people in nursing homes were locked in their rooms in countries including Finland[[5]](#footnote-5), 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 pandemic.

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 homes. 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 investments. Hence, young disabled people live with the constant threat of institutionalisation within nursing homes. A recent decision by the Department of Enterprise excludes home carers from the critical skills exemption to the non-EEA employment permit system. 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.

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1. Comas-Herrera, A. et al (2021). Mortality associated with COVID-19 in care homes: international evidence. International Long-Term Care International. [↑](#footnote-ref-1)
2. 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://coviddrm.org/assets/documents/Disability-Rights-During-the-Pandemic-report-web.pdf. [↑](#footnote-ref-2)
3. Shakespeare, T., Ndagire, F., & Seketi, Q. E. (2021). Triple jeopardy: disabled people and the COVID-19 pandemic. *Lancet (London, England)*. [↑](#footnote-ref-3)
4. 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 [↑](#footnote-ref-4)
5. 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-forrape-of-elderly-woman-in-nursing-home-1.4317757 [↑](#footnote-ref-5)