

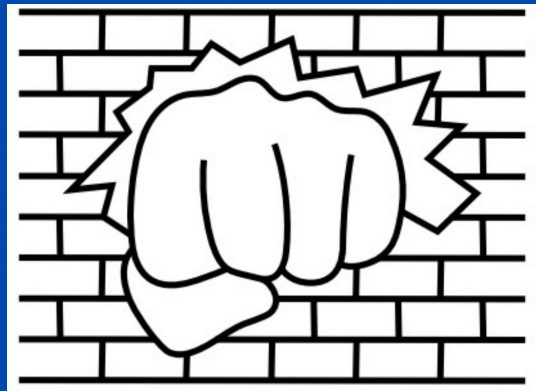
Demands

Freedom Drive 2022



**European Network on Independent Living
#FD2022**

From the 26th to the 28th of September 2022, the European Network on Independent Living – ENIL will hold its 10th edition of the Freedom Drive in Brussels. The Freedom Drive is one of ENIL’s key campaigns – it has taken place every two years since 2003.



ENIL is a Europe-wide network of disabled people. For us, Independent Living is a process of empowerment and emancipation, enabling equal opportunities, rights and full participation in all aspects of society. We advocate for the complete removal of all barriers restricting the inclusion of disabled people in the community.

One of our main goals is the implementation of the UN Convention on the Rights of Persons with Disabilities (UNCRPD) in the European Union. The UNCRPD promotes full participation, independent living and deinstitutionalisation.

The European Union and all 27 Member States ratified the UNCRPD. In the EU, the Convention entered into force in January 2011.

For this **Freedom Drive 2022**, ENIL put together the following **demands** for the European Union, its Member States and other European countries:



DEMAND #1
**Improve access
to Personal Assistance**

Article 19 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) states that all disabled people have “the equal right [...] to live in the community, with choices equal to others”. This does not mean that disabled people have to live alone and without support. According to Article 19(b), “persons with disabilities [must] have access to a range of in-home, residential and other community support services, including personal assistance”.

To close down institutions, governments must increase access of disabled people to community-based services, especially personal assistance (PA). All services must be run according to the human rights model of disability.

General Comment No 5 defines PA as “person-directed, user-led human support”. Personal assistants (PA) provide one-on-one support to disabled people, enabling them to access the same opportunities as non-disabled people.[1] In some European countries, Personal Assistance has been available to disabled people since the 1980s.

The first law on Personal Assistance was introduced in Sweden in 1994. Today, 25 European Union member states have personal assistance schemes. According to those who use Personal Assistance, these schemes are poorly designed and not fully implemented.[2]

With better access to Personal Assistance, more disabled people would be able to leave institutions and would not suffer human rights abuses that happen in these places. Some countries are unable to respond to the increasing demand for Personal Assistance among disabled people. For example, the number of PA users in Slovenia increased by 44% between 2020 and 2021. In Belgium, there is a waiting list of up to 23 years to receive the personal budget needed to hire Personal Assistants.

To be in line with the UNCRPD, Personal Assistance schemes must allow disabled people to choose their assistant, to decide what they do, when, where, and how. Also, disabled people should receive funding to their accounts in the form of a personal budget. The key elements of good PA have been well researched.[3] Personal Assistance is the key tool to Independent Living for many disabled people, including those with intellectual disabilities.

Disabled people who need Personal Assistance must be provided with supported decision making if they need it. Funding for Personal Assistance has to be flexible, so that people can keep their assistants when moving to another region or another country. They should also be able to complain about the result of their application or assessment, so that decisions on PA hours can be legally challenged if needed.

To improve access to Personal Assistance, we recommend the following:

- 1.** The Council of the EU and the European Parliament should adopt a recommendation on Personal Assistance. This recommendation should:
 - Ensure that the EU provides adequate funding for personal assistance schemes that are in line with the UNCRPD and to recommend to the member states to do the same.
 - Set out the legal preconditions needed for good personal assistance.
 - Promote access to personal assistance to disabled people who move to other EU countries, to ensure that all disabled can to live, work and study across the EU if they like.
- 2.** The European Parliament should adopt an “own initiative report”, which will propose that the Council and the Parliament adopt a recommendation on Personal Assistance.
- 3.** The European Commission should define Personal Assistance as the key pillar of community-based services for disabled people in all regulations relevant to EU funding.
- 4.** The European Commission should promote Personal Assistance through all available channels at the European as well as the national level, for example through the European Semester.
- 5.** The European Commission should ensure that Personal Assistance is provided in line with the UNCRPD, by monitoring the projects it funds.

DEMAND #2

End institutionalisation of disabled people

Article 19 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) “recognises the equal right of all persons with disabilities to live in the community with choices equal to others”.^[4] In 2017, the Committee on the Rights of Persons with Disabilities adopted the General Comment No. 5, which states that “state parties have the immediate obligation to [...] replace any institutionalized settings with independent living support services.”^[5]

There is evidence that the number of disabled people living in institutions within the EU has not decreased between 2007 and 2020.^[6] Disabled people across Europe think that the implementation of Article 19 is not good enough. There is concern that no country is prepared to fully implement the Convention.

According to General Comment No 5, all countries that ratified the UNCRPD should “adopt clear and targeted strategies for deinstitutionalisation”. Strategies or plans of action for deinstitutionalisation should contain “specific time frames and adequate budgets, in order to eliminate all forms of isolation, segregation and institutionalisation of persons with disabilities”. Currently, 13 out of 27 EU-countries adopted deinstitutionalisation strategies.^[7]

In all 13 EU countries, disabled people think that their deinstitutionalisation strategy is not good enough. Strategies adopted by governments are often too complicated and it is not clear how deinstitutionalisation will happen—the strategies adopted by Lithuania and Poland are a good example of this.[8] Currently, there is no information at the EU and the national level on how many disabled people live in institutions – this includes nursing homes, psychiatric hospitals, group homes, social care facilities and children’s institutions. Without this information, there is a possibility that not all institutions will be closed.

To end institutionalisation of all disabled people, we recommend the following:

- 1.** The European Union and all Member States should adopt strategies and plans of actions for deinstitutionalisation. For example, the European Union should adopt a Council recommendation and the European Parliament an own initiative report on deinstitutionalisation.
- 2.** Deinstitutionalisation strategies or plans should be legally binding, and in line with the UNCRPD and General Comment No 5. They should include, among other, specific time frames and adequate budgets, and they should be written together with disabled people and their organisations.

3. Deinstitutionalisation strategies should be based on the global “Guidelines for Deinstitutionalisation, including in Emergencies”,^[9] which will be adopted by the Committee on the Rights of Persons with Disabilities in September 2022.

4. The European Union should collect information on the number of disabled people living in institutions – including in nursing homes, psychiatric hospitals, group homes, social care facilities and children’s institutions. This should be collected at both the member state and the EU level.



DEMAND #3
**Use EU funds for
community-based supports and services**

General Comment No 5 states that “no new long-term institutions should be built and that older long-term care residential institutions should not be renovated beyond the most urgent measures necessary”. In addition, “state parties should ensure that public or private funds are not spent on maintaining, renovating, establishing, building or creating any form of institutions or institutionalization”

According to Article 17 of the EU Treaty, the European Commission must “oversee the application of Union law”. The CRPD is part of EU law. In addition, the regulations on the use of EU Funds^[10] states that member states should “respect the obligations set out” in the Convention and that the funds “should not support actions that contribute to any form of segregation or exclusion”.

The CRPD Committee also recommended to the EU “to strengthen the monitoring of the use of the European Structural and Investment Funds”, in order “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”. [11]

There is ample evidence from various sources that the EU is still investing significant financial resources into institutions. [12] Such investments delay the expansion of community-based services for disabled people by maintaining institutions. A report by the EU Ombudsman from April 2022 concluded that “the Commission could take steps to improve the monitoring of ESI-funded activities, and that it should take a more proactive approach to enforcement”. According to the Ombudsman, the Commission must intervene if it becomes aware that a project does not comply with the CRPD and the EU Funds regulations. Currently, the European Commission is not willing to launch infringement procedures when new institutions are being built.[13] The Ombudsman recommended that “the Commission should take a more proactive approach to enforcement, including via infringement procedures, particularly where concerns are raised that ESI-funded activities are at odds with the obligation to promote deinstitutionalisation.”

To ensure that EU funds are used in full compliance with the UNCRPD, we recommend the following:

- 1.** The European Commission should use all instruments at its disposal to enforce the ban of investments of EU funds into all types of institutional settings. To this end, it must closely monitor national spending plans and eliminate all forms of spending on institutions from programmes on the national and the European level. The Commission should intervene and shut down all ongoing projects that fail to promote deinstitutionalisation. We ask the European Commission to implement the full list of recommendations developed by the EU Ombudsman and the Committee on the Rights of Persons with Disabilities.
- 2.** The EU must discontinue all investments into and payments to institutions. To this end, regulations governing the use of EU funds should be drafted in such way to contain a clear ban on spending on institutions of all sizes, including group homes. We ask the European Parliament to produce an own initiative report on how this can be achieved.
- 3.** The EU must provide adequate resources to fund and expand community-based services and supports for disabled people. EU funds should also be used to make community-based services, as well as housing, accessible, affordable and adaptable to every disabled person.

DEMAND #4

Decrease the disability employment gap

Article 27 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) says that “States Parties recognize the right of persons with disabilities to work, on an equal basis with others [...] States Parties shall safeguard and promote the right to work”.

Article 19 of the UNCRPD recognizes “the equal rights of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right”.

According to General Comment No 5, independent living means that disabled people exercise choice and control over their lives. It adds that: “Personal autonomy and self-determination are fundamental to independent living, including access to [...] decent employment”.

There is a big disability employment gap in all EU countries. This means that disabled people are much less likely to be unemployed, compared to non-disabled people. In the EU as a whole, 50,6% of disabled people are employed, compared to 74,8% of non-disabled people. For people with certain impairments, the situation can be even worse. Among 30 million blind and partially sighted people, the unemployment rate is 75%. Among autistic people, only 10% are in employment.[14] According to the ENIL Independent Living Survey from 2020, 96% disabled people and their organisations think that labour market access is either inadequate or requires improvement.

Empirical evidence confirms that sheltered workshops are not a good transitional measure into regular employment. Active labour market policies that use sheltered employment actually decrease disabled people's likelihood to find a job in the open labour market. They therefore increase the disability employment gap. On the other hand, good employment protection legislation increases disabled people's job opportunities. [15]

To decrease the disability employment gap, we recommend the following:

- 1.** Discontinue active labour market policies based on sheltered employment. Sheltered workshops need to be closed and should not benefit from EU funding.
- 2.** Revise the Employment Equality Directive,[16] to bring it in line with the UNCRPD. For example, the Directive should include clear definitions and guidelines on direct and indirect discrimination, as well as reasonable accommodation. The new Directive should specify measures in case of non-compliance and require the adoption of positive action measures.
- 3.** The European Commission should improve implementation of the Employment Equality Directive by starting infringement procedures in case of non-compliance. In addition, the European Labour Authority (ELA) should cooperate with national labour inspectorates to encourage ex-ante investigations into implementation of the Directive; or, it should be able to carry out such inspections itself.

Notes

[1] ENIL 2022b, https://enil.eu/wp-content/uploads/2022/06/Comparison-between-PA-and-CW_final_ENIL.docx

[2] ENIL 2020, https://enil.eu/wp-content/uploads/2022/03/IL-Survey_Summary-report_Dec2020.pdf

[3] Mladenov 2019, <https://www.tandfonline.com/doi/full/10.1080/09687599.2019.1621740>

[4] See UNCRPD, art. 19, <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>

[5] See General Comment no 5, <https://www.ohchr.org/en/documents/general-comments-and-recommendations/general-comment-no5-article-19-right-live>

[6] Comp. Beadle-Brown & Co. 2007, <https://research.kent.ac.uk/tizard/2019/06/11/deinstitutionalisation-and-community-living-outcomes-and-costs/>, and Siska & Co. 2020, <https://deinstitutionalisationdotcom.files.wordpress.com/2020/05/eeg-di-report-2020-1.pdf>

[7] ENIL 2020, https://enil.eu/wp-content/uploads/2022/03/IL-Survey_Summary-report_Dec2020.pdf

[8] Comp. Lithuania 2014, https://socmin.lrv.lt/uploads/socmin/documents/files/pdf/9950_a1-83order.pdf, and Poland 2021, file:///C:/Users/flori/Downloads/Strategia_rozwoju_us%C5%82ug_spo%C5%82ecznych.pdf

[9] CRPD Committee 2022, <https://www.ohchr.org/en/treaty-bodies/crpd/regional-consultations-and-guidelines-deinstitutionalisation-article-19>

[10] Regulation (EU) 2021/1060 of the European Parliament and of the Council of June 2021 (Common Provisions Regulation)

[11] CRPD 2015, <https://documents-dds-ny.un.org/doc/UNDOC/GEN/G15/226/55/PDF/G1522655.pdf?OpenElement>

[12] Comp. ENIL 2022a, <https://enil.eu/wp-content/uploads/2022/06/ENIL-UNCRPD-shadow-report.docx>, Sanden 2020, <https://socialeurope.eu/disability-eu-funding-of-institutions-barely-legal>, and European Ombudsman 2022, <https://www.ombudsman.europa.eu/en/decision/en/155353>

[13] European Commission 2017, [https://eur-lex.europa.eu/legal-content/EN/TXT/HTML/?uri=CELEX:52017XC0119\(01\)&from=EN](https://eur-lex.europa.eu/legal-content/EN/TXT/HTML/?uri=CELEX:52017XC0119(01)&from=EN)

[14] Langensiepen 2021, https://www.europarl.europa.eu/doceo/document/A-9-2021-0014_EN.html

[15] Zwan & Co. 2021, <https://journals.sagepub.com/doi/full/10.1177/09589287211002435>

[16] Council Directive 200/78/EC

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