

# The state of play of independent living and deinstitutionalisation for persons with disabilities in the EU

Progress, challenges, and way forward in supporting community-based living





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## **Abstract**

The right to independent living and community inclusion for the EU's 101 million citizens with disabilities is enshrined in Article 19 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and is further supported by the EU Disability Strategy 2021–2030. This analysis provides a comprehensive overview of the current landscape, ongoing challenges, key stakeholder recommendations, and future political perspectives regarding independent living and deinstitutionalisation.

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# **LIST OF ABBREVIATIONS**

**EASPD** European Association of Service providers for Persons with Disabilities

**EDF** European Disability Forum

**EIGE** European Institute for Gender Equality

**ENIL** European Network on Independent Living

**ESF+** European Social Fund Plus

**ESI** European Structural and Investment

**EU** European Union

FRA Fundamental Rights Agency

**ILA** Independent Living Austria

NGO Non-Governmental Organisations

**RRF** Recovery and Resilience Facility

**UN** United Nations

**UNCRPD** United Nations Convention on the Rights of Persons with Disabilities

**WHO** World Health Organisation

# **EXECUTIVE SUMMARY**

# **Background**

In the European Union (EU) approximately 27% of adults have some form of disability, and despite progress in disability rights, discrimination remains prevalent. Independent living and community inclusion, as outlined in Article 19 of the UN Convention on the Rights of Persons with Disabilities (UNCRPD), are essential for the well-being of the 101 million EU citizens with disabilities. However, barriers persist, with many facing social exclusion, limited access to healthcare and employment, which, in turn, prevents persons with disabilities to live independently. The EU Disability Strategy 2021-2030 aims to improve community-based services, housing, and assistive technologies to support independent living. Yet, challenges such as inadequate funding, outdated infrastructure, continuous national policies of institutionalisation, stigma, misallocation of EU funds, and insufficient support for families remain. As the right to independent living and inclusion within the community are crucial topics to address, a workshop on deinstitutionalisation and independent living of persons with disabilities will be held at the EMPL Committee meeting of 2 December 2024.

#### Aim

This in-depth analysis aims to provide Members with:

- an understanding of the current state of independent living and deinstitutionalisation for people with disabilities in the EU, including the barriers and challenges they face;
- awareness of the objectives of the EU legislation supporting the right to independent living and to community inclusion;
- a summary based on research findings and the input of human rights organisations and EU
  agencies as to ways the EU could better promote, implement and ensure the right to
  independent living and the deinstitutionalisation of persons with disabilities;
- a highlight of future commissioner-designates' commitments towards the rights of persons with disabilities (with a focus on the issues of independent living and institutionalisation) as well as future EU legislation and research on the topic.

## **Key Findings**

In 2023, approximately 27% of adults in the EU had some form of disability, and discrimination remains high, with 54% of people with disabilities reporting unfair treatment. Independent living and inclusion in the community are essential for the well-being of the 101 million EU citizens with disabilities, as enshrined in Article 19 of the UNCRPD. This Article mandates that persons with disabilities have the right to choose where and with whom they live, with access to community-based services to prevent isolation.

General Comment 5, which sets out the States Parties' obligations under Article 19, defines independent living as having control over one's life, including choices around residence, employment, and healthcare, and emphasizes deinstitutionalisation as key. Deinstitutionalisation involves moving away from institutional settings—seen as discriminatory and violative of rights—toward community-based support. However, challenges persist, with many persons with disabilities facing social exclusion, poverty, restricted healthcare and employment access as well as forced placement within institutions or group homes.

As a party to the UNCRPD, the EU must apply the Convention, including Article 19 affirming the right to independent living and inclusion in the community. The EU ratified the Convention in 2011, making it the first human rights convention it joined, and the UNCRPD Committee reviews State compliance with the Convention.

The EU Disability Strategy 2021-2030 aims to improve community-based services, housing, and assistive technologies to support independent living, especially for people currently in institutions. The Strategy highlights access to housing, employment, and affordable long-term care. The EU also emphasises children's rights in its Strategy on the Rights of the Child and the European Child Guarantee, addressing deinstitutionalisation and better support for children with disabilities. Additionally, the European Parliament's 2022 resolution of 13 December 2022 towards equal rights for persons with disabilities urges member states to phase out institutional care, adopt deinstitutionalisation strategies, and ensure that EU funds promote community-based alternatives over institutional settings.

Eurofound reports that institutionalisation has risen significantly in EU Member States, a 29% increase for adults with disabilities over the 10 years preceding the most recent estimate. The UNCRPD Committee, in its 2015 assessment of the situation, urges the EU to improve independent living for people with disabilities, criticising institutionalisation, especially among children, and recommending better monitoring of EU funds to ensure support for community-based services. The EU's latest disability policies include frameworks to promote deinstitutionalisation. However, barriers persist, such as inadequate funding, insufficient national strategies, continuous stigma, outdated infrastructure, and limited support for families, who often take on unsustainable caregiving responsibilities.

Reports highlight an EU trend of establishing group homes, which sometimes replicate institutional conditions rather than offering genuine independence. Moreover, the European Ombudsman calls for better oversight of EU funds to prevent misuse that perpetuates institutional care. The pandemic exposed extreme vulnerabilities within institutions, including high mortality and increased violence against individuals with disabilities. Indeed, key stakeholders such as the European Network on Independent Living (ENIL) point to discriminatory treatment in institutions, especially for those with psychosocial disabilities, who face forced treatment and involuntary placement, infringing on their rights under the UNCRPD.

Key stakeholders and EU agencies recommend involving people with disabilities in policy development and working with Non-Governmental Organisations (NGOs) to support deinstitutionalisation. According to their findings, a person-centred approach, public attitude shifts, and greater visibility of individuals with disabilities are essential for fostering social inclusion. Affordable community housing remains a major barrier, and housing policies must avoid institutional patterns by separating care from accommodation. Inclusive public services, adequate staffing, and support for caregivers are also crucial. Sustained progress requires national strategies with secure, long-term funding and effective monitoring of EU funds to support deinstitutionalisation.

On 20 November 2024, the Commission adopted its guidance on independent living and inclusion in the community of persons with disabilities in the context of EU funding. The guidance offers practical recommendations to Member States on leveraging EU funding to expedite the shift from institutional care to community-based services and independent living for persons with disabilities. Its objective is to turn independent living into a reality by empowering individuals to decide how, where, and with whom they live, ensuring access to diverse community support services, and guaranteeing equal access to services. As new commissioners take office, commitments to

affordable housing, anti-poverty, and equality measures reflect an ongoing EU effort to ensure a barrier-free society. Additionally, the Commission is set to publish a Framework for Social Services of Excellence, which will establish higher standards for community services.

# 1. THE IMPORTANCE AND THE STATE OF PLAY OF INDEPENDENT LIVING

#### **KEY FINDINGS**

In 2023, 27% of the EU population over 16 had a disability, with 54% reporting discrimination due to it. This discrimination contributes to unequal employment rates, a higher propensity of being at-risk-of-poverty and social exclusion and a higher likelihood to have unmet healthcare needs. Article 19 of the UNCRPD guarantees persons with disabilities the right to live independently without discrimination based on their disability. The UNCRPD also calls for deinstitutionalisation, a political and social process aimed at shifting from institutional care and other isolated or segregated settings to independent living. However, institutionalisation remains prevalent, with over 1.29 million people with disabilities still living in institutions, a number largely unchanged since 2007. Persons with intellectual disabilities and complex support needs are particularly affected, with around 750,000 in large care institutions and 39,000 in psychiatric hospitals.

# 1.1. Introduction and definitions

In 2023, 27% of the EU population over the age of 16 had some form of disability, or around one in four adults living in the European Union (EU)<sup>1</sup>. Many persons with disabilities are treated unfairly due to their disability, with the 2023 Discrimination in the EU Eurobarometer revealing that people with disability have a self-reported discrimination rate of 54%, an increase of 4pp since 2019<sup>2</sup>.

For the 101 million people with disabilities, independent living and to be included in community is a crucial element to their well-being. This right is set out in Article 19 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), which requires States Parties to the Convention to ensure that persons with disabilities "have the opportunity to choose their place of residence of where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement"<sup>3</sup>. They must be provided with a range of community-based services "necessary to support living and inclusion in the community and to prevent isolation or segregation". Mainstream services and facilities must also be made accessible "on an equal basis to persons with disabilities" and "responsive to their needs".

<u>General Comment 5</u> on living independently and being included in the community sets out the States Parties' obligations under Article 19, and is **key to promoting implementation of the right to independent living in practice**. It includes, among other, definitions of independent living, institutional care and personal assistance<sup>4</sup>.

According to the General Comment 5, independent living means that "individuals with disabilities are provided with all necessary means to enable them to exercise choice and control over their lives and make all decisions concerning their lives. Personal autonomy and self-

European Council, 2024, Disability in the EU: facts and figures, European Council. Available at: https://www.consilium.europa.eu/en/infographics/disability-eu-facts-figures/.

<sup>&</sup>lt;sup>2</sup> Eurostat, 2023, *Discrimination in the European Union*, Eurobarometer. Available at: https://europa.eu/eurobarometer/surveys/detail/2972.

United Nations, 2006, *Article 19 – Living independently and being included in the community*, Convention on the Rights of Persons with Disabilities (CRPD), United Nations. Available at: <a href="https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-19-living-independently-and-being-included-in-the-community.html">https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-19-living-independently-and-being-included-in-the-community.html</a>.

<sup>&</sup>lt;sup>4</sup> European Network on Independent Living (ENIL), 2022, Independent living, ENIL. Available at: https://enil.eu/independent-living/.

determination are fundamental to independent living, including access to transport, information, communication and personal assistance, place of residence, daily routine, habits, decent employment, personal relationships, clothing, nutrition, hygiene and health care, religious activities, cultural activities and sexual and reproductive rights<sup>15</sup>.

In order for persons with disabilities to have autonomy and agency over their lives, the UNCRPD advocates for deinstitutionalisation. Indeed, the UNCRPD 2022 guidelines on deinstitutionalization, describes institutionalisation as "a discriminatory practice against persons with disabilities, contrary to article 5 of the Convention. It involves de facto denial of the legal capacity of persons with disabilities, in breach of article 12. It constitutes detention and deprivation of liberty based on impairment, contrary to article 14. States parties should recognize institutionalization as a form of violence against persons with disabilities. It exposes persons with disabilities to forced medical intervention with psychotropic medications, such as sedatives, mood stabilizers, electro-convulsive treatment, and conversion therapy, infringing articles 15, 16 and 17. It exposes persons with disabilities to the administration of drugs and other interventions without their free, prior and informed consent, in violation of articles 15 and 25 (...) Institutionalization contradicts the right of persons with disabilities to live independently and be included in the community" <sup>6</sup>.

According to the General Comment, institutions can include facilities with more than a hundred residents, but also group homes with five to eight individuals, if these homes continue to isolate residents and deny them control over how they live their life<sup>7</sup>.

For children, any placement outside of a family is considered an institution. According to General Comment 5, "large or small group homes are particularly harmful for children, who need the unique environment provided by a family". It further emphasises that "family-like institutions are still institutions and cannot substitute for care by a family."

Deinstitutionalisation is both a political and social process aimed at shifting from institutional care and other isolated or segregated settings to independent living. The development of community-based services requires a holistic approach, involving policy measures to ensure that public services—such as housing, education, transport, healthcare, and other forms of support—are accessible to disabled people within mainstream settings<sup>8</sup>.

For the European Association of Service providers for Persons with Disabilities (EASPD), independent living in the community (as opposed to in an institution, group homes and social exclusion) means having access to adequate healthcare, social care, and support systems, as well as personal assistance services<sup>9</sup>. It also involves access to employment, education,

Committee on the Rights of Persons with Disabilities, 2017, General comment No. 5 (2017) on living independently and being included in the community, United Nations. Available at: https://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=6QkG1d%2fPPRiCAqhKb7yhsnbHatvuFkZ%2bt93Y3D%2baa2q6qfz Oy0vc9Qie3KjjeH3GA0srJgyP8IRbCjW%2fiSqmYQHwGkfikC7stLHM9Yx54L8veT5tSkEU6ZD3ZYxFwEgh.

<sup>&</sup>lt;sup>6</sup> Office of the High Commissioner for Human Rights, 2022, *CRPD/C/5: Guidelines on deinstitutionalization, including in emergencies* (2022), United Nations. Available at: <a href="https://www.ohchr.org/en/documents/legal-standards-and-guidelines/crpdc5-guidelines-deinstitutionalization-including">https://www.ohchr.org/en/documents/legal-standards-and-guidelines/crpdc5-guidelines-deinstitutionalization-including</a>.

European Disability Forum (EDF), 2023, *Independent living and de-institutionalisation Policy*, EDF. Available at: <a href="https://www.edf-feph.org/independent-living-and-de-institutionalisation-policy/">https://www.edf-feph.org/independent-living-and-de-institutionalisation-policy/</a>.

European Network on Independent Living (ENIL), 2022, Deinstitutionalisation, ENIL. Available at: <a href="https://enil.eu/deinstitutionalisation/">https://enil.eu/deinstitutionalisation/</a>.

European Association of Service providers for Persons with Disabilities (EASPD), 2022, Independent Living and Inclusion in the Community for Persons with Disabilities, EASPD. Available at: https://easpd.eu/fileadmin/user\_upload/Publications/Independent\_Living\_and\_Inclusion\_in\_the\_Community\_Position\_Paper\_-\_EASPD.pdf.

transport, buildings, and information. Additionally, it encompasses having a sufficient income, necessary assistive technologies, housing that can be adapted to individual needs, and opportunities for self-advocacy and peer networks.

# 1.2. The situation of persons with disabilities in the EU: discrimination and institutionalisation data

Many persons with disabilities face social exclusion (i.e. "a situation whereby a person is prevented (or excluded) from contributing to and benefiting from economic and social progress" 10). Indeed, in 2023, the disability employment gap was of 21.5pp 11, the disability at risk of poverty or social exclusion gap was of 10.8pp, and people with disabilities were four times more likely to have unmet healthcare needs 12. In the EU 27, about 22.4% of persons with disabilities were living in households with a low work intensity in 2020, compared with 6.6% of persons without disabilities 13. Additionally, people with disabilities in the workforce are more likely to hold temporary contracts, earn lower wages, and face higher risks of job loss during economic downturns. As a result, they have reduced access to employment-based social security, leaving them particularly vulnerable to poverty 14. This, in turn, does not allow for persons with disabilities to live independently within their communities.

Table 1: Gender and disability equality index according to the European Institution for Gender Equality (EIGE), 2023

	Women with disabilities	Men with disabilities	Women without disabilities	Men without disabilities
Mean monthly earnings (PPS, +16 working population)	1885	2334	2045	2658
At-risk-of-poverty (%, 16+ population)	22	20	16	15
Full-time equivalent employment rate (%, 15-89 population)	42	57	34	38
Graduates of tertiary education (%, 15-89 population)	17	18	32	29

European Commission, Glossary - social exclusion, European Commission. Available at: https://home-affairs.ec.europa.eu/networks/european-migration-network-emn/emn-asylum-and-migration-glossary/glossary/social-exclusion\_en.

Eurostat, 2024, Disability employment gap by level of activity limitation and sex, Eurostat. Available at: <a href="https://ec.europa.eu/eurostat/databrowser/view/tepsr\_sp200/default/table?lang=en">https://ec.europa.eu/eurostat/databrowser/view/tepsr\_sp200/default/table?lang=en</a>.

European Council, 2024, Disability in the EU: facts and figures. Available at: https://www.consilium.europa.eu/en/infographics/disability-eu-facts-figures/.

European Commission and Grammenos, S., 2023, European comparative data on persons with disabilities – Statistics – Data 2020 – Summary and conclusions, Publications Office of the European Union. Available at: <a href="https://op.europa.eu/en/publication-detail/-/publication/1b84b7c4-8504-11ee-99ba-01aa75ed71a1/language-en">https://op.europa.eu/en/publication-detail/-/publication/1b84b7c4-8504-11ee-99ba-01aa75ed71a1/language-en</a>.

European Network for Independent Living (ENIL), 2022, Shadow report on the implementation of the UN Convention on the Rights of Persons with Disabilities in the European Union, ENIL. Available at: <a href="https://easpd.eu/fileadmin/user\_upload/Publications/Independent\_Living\_and\_Inclusion\_in\_the\_Community\_Position\_Paper\_-\_EASPD.pdf">https://easpd.eu/fileadmin/user\_upload/Publications/Independent\_Living\_and\_Inclusion\_in\_the\_Community\_Position\_Paper\_-\_ EASPD.pdf</a>.

	Women with disabilities	Men with disabilities	Women without disabilities	Men without disabilities
Self-perceived health, good or very good (%, 16+ population)	19	22	84	86
Population with unmet needs for medical examination (%, 16+ population)	11	10	3	2

Source: Gender Equality Index.

The 2020 report from the European Expert Group on Transition from Institutional to Community-Based Care, found that there were at least 1,294,253 children and adults with disabilities and mental health problems living in institutions <sup>15</sup>. The report also shows that the number of people in institutions has not known much evolution in the past decade (in 2007, the number of persons in institutions was calculated to be of 1,286,059). Eurofound's most recent study shows that, across the 24 Member States where comparison over time is possible, the number of adults with disabilities living in residential institutions increased by 29% over the 10 years preceding the most recent estimate (from 709,682 previously to 916,385)<sup>16</sup>. The number of persons with disabilities in institutions across EU Member States has varied significantly, with countries like France seeing a 100% increase in adults residing in residential institutions over the past 10 years, while Finland has experienced a 60% decrease (see Figure 1). Certain countries, such as Croatia, Ireland and Romania show relative positive change in institutionalisation over time from 2009 for children and adults with disabilities (see Table 2). However, Member States like Italy and Luxembourg show no progress in deinstitutionalisation (see Table 2).

Moreover, research reveals that persons with intellectual disabilities and with complex support needs are most likely to live in institutions, with Inclusion Europe finding that in 2023 around 750,000 people with intellectual disabilities were living in segregated "care" institutions with 30 persons or more in one place and 39 000 in psychiatric hospitals <sup>17</sup>.

However, it is important to note that data on institutionalisation numbers is very complicated to track and often lacks precision, due to variations in how countries define, report, and categorise institutional care across the EU<sup>18,19</sup>. Many Member States do not systematically collect or share disaggregated data<sup>20</sup>. Additionally, differing definitions of "institutions" versus community-based settings make comparisons challenging. The **absence of standardised reporting mechanisms means that the actual numbers may be under- or overestimated, complicating efforts to** 

Siška. J and Beadle-Brown. J., (European Expert Group on Transition from Institutional to Community-Based Care), Report on the transition from institutional care to community-based services in 27 EU Member States, Inclusion Europe. Available at: <a href="https://www.inclusion-europe.eu/wp-content/uploads/2020/01/eeg-di-report-2020-1.pdf">https://www.inclusion-europe.eu/wp-content/uploads/2020/01/eeg-di-report-2020-1.pdf</a>.

<sup>&</sup>lt;sup>16</sup> Eurofound, 2024, *Paths towards independent living and social inclusion in Europe*, Publications Office of the European Union, Eurofound. Available at: <a href="https://www.eurofound.eu/en/publications/2024/paths-towards-independent-living-and-social-inclusion-europe">https://www.eurofound.europa.eu/en/publications/2024/paths-towards-independent-living-and-social-inclusion-europe</a>.

European Disability Forum (EDF), 2024, European Human Rights Report - Legal capacity: Personal choice and control, EDF. Available at: <a href="https://www.edf-feph.org/content/uploads/2004/08/Human-Rights-Report-2024-Legal-Capacity-Final.pdf">https://www.edf-feph.org/content/uploads/2004/08/Human-Rights-Report-2024-Legal-Capacity-Final.pdf</a>.

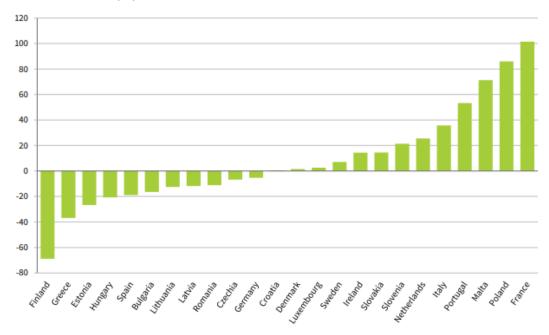
European Parliament, 2021, Resolution of 7 October 2021 on the protection of persons with disabilities through petitions: lessons learnt, EUR-LEX. Available at: <a href="https://www.europarl.europa.eu/doceo/document/TA-9-2021-0414">https://www.europarl.europa.eu/doceo/document/TA-9-2021-0414</a> EN.html.

Eurochild, 2021, DataCare: how the EU can better monitor deinstitutionalisation progress, Eurochild. Available at: <a href="https://eurochild.org/news/datacare-how-the-eu-can-better-monitor-deinstitutionalisation-progress/">https://eurochild.org/news/datacare-how-the-eu-can-better-monitor-deinstitutionalisation-progress/</a>.

The European Expert Group on the Transition from Institutional to Community-based Care (EEG), 2022, Deinstitutionalisation should remain a priority for EU funding, EEG. Available at: <a href="https://deinstitutionalisation.com/2022/03/15/deinstitutionalisation-should-remain-a-priority-for-eu-funding/">https://deinstitutionalisation.com/2022/03/15/deinstitutionalisation-should-remain-a-priority-for-eu-funding/</a>.

# assess the true scope of institutionalisation and to monitor progress towards deinstitutionalisation goals effectively<sup>21</sup>.

Figure 1: Change in the population of adults (aged 18–64) with disabilities in residential institutions over the 10 years preceding the most recent estimate, EU Member States (%)



Source: Eurofound.

Table 2: Summary of change in institutionalisation over time from 2009 (or as close to that year as data available) for each EU country, 2020

Country	Children with disabilities	Adults with disabilities	Adults with mental health problems
Austria	ND	NC	•
Belgium	ND	ND	•
Bulgaria	Ţ	NC	NC
Croatia	+	+	NC
Cyprus	ND	NC	NC
Czechia	NC	•	NC
Denmark	ND	NC	ND
Estonia	NC		ND
Finland		•	ND

21 Ibid.

Country	Children with disabilities	Adults with disabilities	Adults with mental health problems
France	NC	<b>1</b>	ND
Germany	ND	ND	ND
Greece	<b>1</b>	NC	<b>↓</b>
Hungary	I I	NC	
Ireland	•	•	
Italy	1	ND	ND
Latvia	•	I I	•
Lithuania	•	•	ND
Luxembourg	ND	1	ND
Malta	ND	ND	NC
Netherlands	ND		Ţ
Poland	•	NC	NC
Portugal	ND	1	Ţ
Romania	-	NC	Į.
Slovakia	NC	•	NC
Slovenia	•	ND	ND
Spain	ND	ND	ND
Sweden	NA	NA	NA

Key: ND = no data available to determine change; NA = not applicable as institutional services no longer used; = increase in institutional services; = slight increase in institutional services; = slight decrease in institutional services; = slight

Source: Report on the transition from institutional care to community-based services in 27 EU Member States.

# 2. LEGAL AND POLICY FRAMEWORK

## **KEY FINDINGS**

The EU is committed to implementing the UNCRPD, which guarantees the right of persons with disabilities to live independently and be included in the community. Indeed, Article 19 of the UNCRPD, General Comment 5 on living independently and being included in the community, and the 2022 guidelines on deinstitutionalisation define the right of persons with disabilities to live autonomously, be included in the community, and access a range of community-based services that prevent isolation and segregation, setting clear obligations for states to transition away from institutional care.

The 2021-2030 EU Disability Strategy focuses on promoting independent living and addressing gaps in community-based services, housing, and personal assistance. The European Parliament's 2022 resolution and the 2023 Commission communication emphasise phasing out institutional care and investing in inclusive, community-based alternatives, with support from EU funding and technology. The EU Strategy on the Rights of the Child and the European Child Guarantee, also highlight the need for inclusive services and independent living for children with disabilities.

# 2.1. The UN Convention on the Rights of Persons with Disabilities (UNCRPD)

As a Party to the UNCRP, the European Union is obligated to implement the Convention within its scope of competence. The UNCRPD, adopted on 13 December 2006 and in force since 3 May 2008, does not create new rights but ensures that existing civil, cultural, economic, political, and social rights are applied with respect to disability. The EU ratified the Convention, which entered into force on 22 January 2011, making it the first international, legally binding instrument to establish minimum standards for the rights of people with disabilities, and the first human rights convention the EU has joined.

Article 34 of the Convention establishes the **Committee on the Rights of Persons with Disabilities, comprised of 18 independent experts** who monitor the UNCRPD's implementation and report to the UN General Assembly every two years. State Parties must submit reports to the Committee on their progress in fulfilling the Convention's obligations, initially within two years of ratification and then at least every four years, or upon request. The Committee reviews these reports, along with alternative reports from civil society organizations, and issues concluding observations and recommendations. The first EU review of UNCRPD implementation concluded in 2015 with the adoption of the Committee's Concluding Observations.

The right to live independently and to be included in community is set out in <u>Article 19</u> of the UNCRPD<sup>22</sup>. According to the Committee on the Rights of Persons with Disabilities (UNCRPD Committee), Article 19 is "one of the widest ranging and most intersectional articles" and "integral for the implementation of the Convention across all articles"<sup>23</sup>. General Comments, adopted by the UNCRPD Committee, provide authoritative guidance to the States Parties, and should be used by them to interpret their obligations under the UNCRPD. General Comment

United Nations, 2006, *Article 19 – Living independently and being included in the community*, Convention on the Rights of Persons with Disabilities (CRPD), United Nations. Available at: <a href="https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-19-living-independently-and-being-included-in-the-community.html">https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-19-living-independently-and-being-included-in-the-community.html</a>.

<sup>&</sup>lt;sup>23</sup> European Network on Independent Living (ENIL), 2022, Independent living, ENIL. Available at: https://enil.eu/independent-living/.

**5** goes into more detail on how to interpret UNCRPD Article 19 and is key to promoting implementation of the right to independent living in practice<sup>24</sup>.

Additionally, the UNCRPD published in 2022 a set of <u>Guidelines on deinstitutionalization</u>, <u>including in emergencies</u>, to complement the Committee's general comment No. 5 and its guidelines on the right to liberty and security of persons with disabilities (art. 14)<sup>25</sup>. The guidelines are designed to help and advise States in realising the right of persons with disabilities to live independently and be included in the community, as well as to support planning for deinstitutionalisation and preventing new cases of institutionalisation. They incorporate insights from the experiences of persons with disabilities before and during the COVID-19 pandemic</u>, which exposed the widespread nature and negative impacts of institutionalisation. The pandemic underscored the harm institutions can inflict on the rights and wellbeing of persons with disabilities, who may face violence, neglect, abuse, and restraints in such settings.

Developed through a participatory approach, these guidelines reflect input from seven regional consultations organised by the Committee.

Committee on the Rights of Persons with Disabilities, 2017, General comment No. 5 (2017) on living independently and being included in the community, United Nations. Available at: <a href="https://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=6QkG1d%2fPPRiCAqhKb7yhsnbHatvuFkZ%2bt93Y3D%2baa2q6qfz">https://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=6QkG1d%2fPPRiCAqhKb7yhsnbHatvuFkZ%2bt93Y3D%2baa2q6qfz</a>
<a href="https://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=6QkG1d%2fPPRiCAqhKb7yhshbaa2q6qfz">https://docstore.ohchr.org/SelfServ

Office of the High Commissioner for Human Rights, 2022, CRPD/C/5: Guidelines on deinstitutionalization, including in emergencies (2022), United Nations. Available at: <a href="https://www.ohchr.org/en/documents/legal-standards-and-quidelines/crpdc5-guidelines-deinstitutionalization-including">https://www.ohchr.org/en/documents/legal-standards-and-guidelines/crpdc5-guidelines-deinstitutionalization-including</a>.

Figure 2: Article 19 and Article 14 of the UNCRPD and a selected extract of General Comment 5 related to Article 19 of the UNCRPD

# Article 19 – Living independently and being included in the community

States Parties to the present Convention recognize the equal right 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 and their full inclusion and participation in the community, including by ensuring that:

- a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;
- b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;
- c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

# General comment No. 5 (2017) on living independently and being included in the community

- 1. Persons with disabilities have historically been denied their personal and individual choice and control across all areas of their lives (...) This has led to abandonment, dependence on family, institutionalization, isolation and segregation.
- 2. Article 19 of the Convention on the Rights of Persons with Disabilities recognizes the equal right of all persons with disabilities to live independently and be included in the community, with the freedom to choose and control their lives (...)
- 4. Independent living and inclusive life in the community are ideas that historically stemmed from persons with disabilities asserting control over the way they want to live by creating empowering forms of support such as personal assistance and requesting that community facilities be in line with universal design principles
- 5. (...) The cost of social exclusion is high as it perpetuates dependency and thus interference with individual freedoms. Social exclusion also engenders stigma, segregation and discrimination, which can lead to violence, exploitation and abuse in addition to negative stereotypes that feed into a cycle of marginalization of persons with disabilities. Policies and concrete plans of action for social inclusion of persons with disabilities, including through the promotion of their right to independent living (art. 19), represent a cost-effective mechanism to ensure the enjoyment of rights, sustainable development and a reduction in poverty.

#### Article 14 - Liberty and security of person

- 1. States Parties shall ensure that persons with disabilities, on an equal basis with others:
- a) Enjoy the right to liberty and security of person;
- b) Are not deprived of their liberty unlawfully or arbitrarily, and that any deprivation of liberty is in conformity with the law, and that the existence of a disability shall in no case justify a deprivation of liberty.
- 2. States Parties shall ensure that if persons with disabilities are deprived of their liberty through any process, they are, on an equal basis with others, entitled to guarantees in accordance with international human rights law and shall be treated in compliance with the objectives and principles of the present Convention, including by provision of reasonable accommodation.

Source: United Nations<sup>26,27,28</sup>.

# 2.2. EU legislation supporting independent living and inclusion within the community

The principles of independent living and social inclusion are core to several EU recommendations and regulations. The <u>European Pillar of Social Rights</u> highlights the importance of <u>supporting</u> independent living for people with disabilities (Principle 17), providing affordable long-term care services (Principle 18), and ensuring the right to housing and support for the homeless (Principle 19) to the promotion of social inclusion<sup>29</sup>.

In March 2021, the European Commission adopted the <u>Strategy for the Rights of Persons with</u> <u>Disabilities 2021-2030</u><sup>30</sup>. This ten-year strategy aims to enhance the lives of people with disabilities both in Europe and globally.

In this document, the Commission sets out to ensure decent quality of life and living independently and to develop independent living and reinforcing community-based services. In its seventh priority, the Strategy focuses on ensuring that persons with disabilities, regardless of age, have the right to live independently and be fully included in their communities, with choices about where, how, and with whom they live. However, many people with disabilities, particularly those living in institutions, remain excluded from community life due to a lack of appropriate community-based services, housing, and personal assistance—challenges that have been exacerbated in rural areas and intensified by the COVID-19 pandemic. The Strategy acknowledges these gaps and calls for stronger action to improve the availability and quality of community services, housing, and technical aids, while addressing workforce shortages and unequal service quality across Member States.

In response, the European Commission will support national, regional, and local authorities in advancing deinstitutionalisation and promoting independent living through various funding mechanisms, such as the 2021-2027 shared management funds and the Recovery and Resilience Plans. Furthermore, the green and digital transitions offer opportunities to enhance services for people with disabilities, leveraging technologies like artificial intelligence and robotics, if accessibility barriers are removed and digital skills are improved.

On 20 November 2024, the **Commission adopted its <u>Guidance on independent living and inclusion in the community of persons with disabilities in the context of EU funding**. The guidance is a so-called 'flagship' initiative of the Strategy for the Rights of Persons with Disabilities 2021-2030. The guidance offers practical recommendations to Member States on the use of EU</u>

United Nations, 2006, *Article 19 – Living independently and being included in the community*, Convention on the Rights of Persons with Disabilities (CRPD), United Nations. Available at: <a href="https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-19-living-independently-and-being-included-in-the-community.html">https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-19-living-independently-and-being-included-in-the-community.html</a>.

<sup>27</sup> Committee on the Rights of Persons with Disabilities, 2017, General comment No. 5 (2017) on living independently and being included in the community, United Nations. Available at: https://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=6QkG1d%2fPPRiCAqhKb7yhsnbHatvuFkZ%2bt93Y3D%2baa2q6qfz Oy0vc9Qie3KjjeH3GA0srJgyP8IRbCjW%2fiSqmYQHwGkfikC7stLHM9Yx54L8veT5tSkEU6ZD3ZYxFwEgh.

United Nations, 2006, Article 14 – Liberty and security of person, Convention on the Rights of Persons with Disabilities (CRPD), United Nations. Available at:
<a href="https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-14-liberty-and-security-of-person.html">https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-14-liberty-and-security-of-person.html</a>.

European Commission, 2021, The European Pillar of Social Rights Action Plan, EUR-LEX. Available at: https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=celex%3A52021DC0102.

European Commission, 2021, *Union of Equality: Strategy for the Rights of Persons with Disabilities 2021-2030*, European Commission. Available at: https://ec.europa.eu/social/main.jsp?catId=738&langId=en&pubId=8376&furtherPubs=yes.

funding to accelerate the transition from institutional care to community-based services and independent living for persons with disabilities (in accordance to Article 19 of the UNCRPD and applicable EU law). The Commission, in its guidance, emphasises the **need to redirect resources** from institutional care to community-based services and accessible housing, aligning with a human rights-based, social model of inclusion<sup>31</sup>. It highlights the importance of individualised plans, the phased closure of institutional services, and the establishment of strategic frameworks with clear timelines, targets, and budgets. The guidance underscores the role of person-centred approaches, personal assistance, home care, and accessible technology in fostering independent living. Additionally, it stresses the importance of addressing barriers to employment, education, and social participation to ensure financial independence, alongside robust governance, workforce development, and active consultation with persons with disabilities to create inclusive, effective policies and services. It adds that progress in monitoring, through improving the collection of disaggregated data, is important to move towards deinstitutionalisation.

Additionally, the Commission is programmed to release a **Framework for Social Services of Excellence to improve the quality of community-based services**, for 2024 also.

On the specific case of children, the **EU Disability Strategy recognises that children with disabilities need particular attention**<sup>32</sup>. It adds that mainstream support services need to be inclusive of and accessible for children with disabilities. It further **addresses deinstitutionalisation**, **safety, and protection**.

The <u>EU Strategy on the Rights of the Child</u> explicitly mentions that it is anchored to the CRPD and commits to ensuring complementarity with the EU Disability Strategy to respond to the **needs of children with disabilities and provide better access to mainstream services and independent living**<sup>33</sup>. Indeed, within the strategy the Commission invites Member States to "promote national strategies and programmes to speed up de-institutionalisation and the transition towards quality, family- and community-based care services including with an adequate focus on preparing children to leave care, including for unaccompanied migrant children"<sup>34</sup>.

In addition, the <u>European Child Guarantee</u> calls on Member States to prioritise children with disabilities and those in alternative care, including institutional settings, within their national integrated measures<sup>35</sup>. Furthermore, the Council Recommendation underscores the **promotion of quality community-based or family-based care** as part of efforts towards the deinstitutionalisation of children, and **supports children's transition out of institutional care to foster independent living and social integration**. However, the Recommendation does not disallow for the institutionalisation of children and states 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"<sup>36</sup>.

Recently, was adopted, the European Parliament resolution of 13 December 2022 towards

<sup>31</sup> Ibid.

<sup>&</sup>lt;sup>32</sup> European Commission, 2021, *Union of Equality: Strategy for the Rights of Persons with Disabilities 2021-2030*, European Commission. Available at: <a href="https://ec.europa.eu/social/main.jsp?catid=738&langld=en&publd=8376&furtherPubs=yes">https://ec.europa.eu/social/main.jsp?catid=738&langld=en&publd=8376&furtherPubs=yes</a>.

European Commission, 2021, EU strategy on the rights of the child, EUR-LEX. Available at: https://eur-lex.europa.eu/legal-content/en/TXT/?uri=CELEX%3A52021DC0142.

<sup>34</sup> Ibid.

European Council, 2021, Council Recommendation (EU) 2021/1004 of 14 June 2021 establishing a European Child Guarantee, EUR-LEX. Available at: https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX%3A32021H1004.

<sup>36</sup> Ibid

equal rights for persons with disabilities and receive appropriate community-based services (...) only be fully guaranteed if policies and legislation that offer alternatives to institutions are developed at national, regional and local levels, and are guided by European standards", and calls "on the Commission and the Member States to phase out institutional care settings for persons with disabilities as soon as possible [...] on the Member States to adopt deinstitutionalisation strategies and to ensure that their laws, policies and programmes on deinstitutionalisation are in line with the concept of independent living set out in the CRPD". The resolution also addresses the essential subject of EU funding in its sixth paragraph, "relevant EU funds should aim to promote inclusive, accessible environments, services, practices and devices, following a universal design approach and favouring deinstitutionalisation, including strong support for personal assistance and independent living" and recalls in its eighth article "that the Common Provisions Regulation for 2021-2027 outlines that the European Social Fund and the European Regional Development Fund must be used in a manner which is compliant with the EU's social inclusion policies; calls, therefore, for stricter provisions prohibiting the investment of EU funds into institutional care settings".

Moreover, the European Parliament has highlighted the importance of independent living and right to be included in communities, through:

- Resolution of 10 March 2021 on the implementation of Council Directive 2000/78/EC establishing a general framework for equal treatment in employment and occupation in light of the UNCRPD<sup>38</sup>:
  - "Calls on the Commission and the Member States to urgently put in place measures to (...) underlines, furthermore, the importance of providing appropriate support to PwD throughout their lives, making better use of innovative technologies to level the playing field and remove barriers to education and employment, and to help PwD gain access to digital tools and software that are indispensable for their independent living"
  - "Calls on the Commission and the Member States to recognise and promote user-led personal assistance in line with General Comment No 5 of the UNCRPD Committee, to foster independent living and inclusion in the labour market"
- Resolution of 7 October 2021 on the protection of persons with disabilities through petitions: lessons learnt<sup>39</sup>:
  - "whereas the progress in deinstitutionalisation is uneven across the Member States and whereas despite the introduction of relevant policies and the allocation of substantial funding in the EU (...) whereas Member States must speed up the process of deinstitutionalisation and the Commission must carefully monitor their progress"

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European Parliament, Resolution of 13 December 2022 towards equal rights for persons with disabilities, European Parliament. Available at: https://www.europarl.europa.eu/doceo/document/TA-9-2022-0435\_EN.html.

European Parliament, 2021, Resolution of 10 March 2021 on the implementation of Council Directive 2000/78/EC establishing a general framework for equal treatment in employment and occupation in light of the UNCRPD, EUR-LEX. Available at: <a href="https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX:52021IP0075">https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX:52021IP0075</a>.

<sup>&</sup>lt;sup>39</sup> European Parliament, 2021, Resolution of 7 October 2021 on the protection of persons with disabilities through petitions: lessons learnt, EUR-LEX. Available at: <a href="https://www.europarl.europa.eu/doceo/document/TA-9-2021-0414">https://www.europarl.europa.eu/doceo/document/TA-9-2021-0414</a> EN.html.

- "highlights the need for commonly accepted definitions of disability, deinstitutionalisation, living in the community, independent living and inclusive education; encourages the Member States to strengthen coordination mechanisms"
- "Recalls that many people with disabilities are still segregated from community life and do not have control over their daily lives, in particular those living in residential institutions, as the COVID-19 pandemic has highlighted and intensified the challenges faced by the latter; urges the Member States to mainstream support services in order to ensure people with disabilities enjoy the equal right to live independently and be included in the community"
- "reiterates the need for mutual understanding of deinstitutionalisation, its implementation and independent living in the community, with a view to better aligning the Member States' strategies and the EU funds with the CRPD"
- "calls on the Member States to ensure a process that provides for a shift in living arrangements for persons with disabilities, from institutional settings to a system enabling social participation and in which services are provided in the community according to individual will and preference; calls on the Member States to include specific targets with clear deadlines in their deinstitutionalisation strategies and to adequately finance the implementation of these strategies"
- "Calls on the Commission and the Member States to include in the final content of the partnership agreements on the European Structural and Investment Funds and in these funds' programmes objectives and approaches that improve the living conditions of persons with disabilities(...) including in supporting the transition from institutional to community-based living; asks the Commission to monitor closely the use of EU funds in line with the CRPD"
- Resolution of 18 June 2020 on the European Disability Strategy post-2020<sup>40</sup>:
  - "Calls on the Commission to actively promote the transition from institutional and/or segregating care to community-based support, including personal assistance, and inclusive services (both mainstream and tailor-made), in all EU policy tools and initiatives; calls, further, on the Commission to ensure that overall progress in deinstitutionalisation is included as an indicator in the EU social scoreboard"
  - o "Calls on the Member States to foster participation by accelerating the deinstitutionalisation process within a specific time frame and by replacing substitute decision-making by supported decision-making; calls on the Member States to ensure that deinstitutionalisation never leads to homelessness for persons with disabilities because of a lack of adequate and/or accessible housing"
  - "Calls on the Commission to safeguard the CRPD-compliant use of EU funds and to ensure that EU funds do not contribute to the construction or refurbishment of institutional care settings or any other kind of settings that could easily turn into an institution, or to projects that do not meaningfully involve persons with

<sup>&</sup>lt;sup>40</sup> European Parliament, 2020, *Resolution of 18 June 2020 on the European Disability Strategy post-2020, Official Journal of the European Union*. Available at: <a href="https://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=CELEX:52020IP0156">https://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=CELEX:52020IP0156</a>.

**disabilities, their representative family members and organisations**, and are not invested in structures that are inaccessible to persons with disabilities"

"Insists that EU funds should aim to (...) favouring deinstitutionalisation, including strong support for personal assistance and independent living"

Additionally, the <u>2023 Commission communication on a comprehensive approach to mental</u> <u>health</u> underscores the connection between disabilities and mental health challenges, emphasising the importance of developing effective deinstitutionalisation practices in this area<sup>41</sup>.

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<sup>&</sup>lt;sup>41</sup> European Commission, 2023, *Commission communication on a comprehensive approach to mental health*, European Commission. Available at:

https://health.ec.europa.eu/document/download/cef45b6d-a871-44d5-9d62-3cecc47eda89 en?filename=com 2023 298 1 act\_en.pdf.

# 3. PROGRESS AND CHALLENGES REGARDING INDEPENDENT LIVING AND DESINSTITUTIONALISATION

## **KEY FINDINGS**

In 2015, the UN Committee on the Rights of Persons with Disabilities (UNCRPD) acknowledged the EU's efforts in ratifying the UNCRPD but raised concerns about the rights of persons with disabilities, particularly in institutions and regarding the lack of inclusive education and support. In 2015, the Committee urged the EU to enhance community-based services and prevent institutionalisation.

In 2022, the UNCRPD Committee requested an update, and the EU responded by highlighting its support for deinstitutionalisation through the 2021-2027 cohesion policy, though it noted that EU funds still allow for investment in institutions. The EU also reaffirmed its commitment to supporting children with disabilities and promoting independent living.

Despite progress, barriers to deinstitutionalisation remain, including inadequate funding, outdated infrastructure, and stigma. The COVID-19 pandemic exposed the vulnerabilities of persons with disabilities in institutions. This led the UNCRPD Committee to publish in 2022 Guidelines on deinstitutionalization, including in emergencies. The UNCRPD Committee as well as multiple other organisations express concern about the institutionalisation of individuals, especially those with psychosocial and intellectual disabilities, violating their rights to make informed decisions about their care.

# 3.1. Issues raised by the Committee on the Rights of Persons with Disabilities

In 2015, the **Committee on the Rights of Persons with Disabilities issued concluding observations on the initial report of the EU**<sup>42</sup>. The UNCRPD Committee underscores the EU's positive steps toward ratifying a UN human rights treaty and promoting non-discrimination through the EU Charter of Fundamental Rights.

However, it also raises several concerns regarding the fulfilment of the right to independent living. It notes that many children with disabilities remain in institutions without access to inclusive, quality education, and that austerity measures have limited support for families. The Committee urges the EU to ensure community-based support services, prevent new institutionalisations, and prioritise inclusive education. Additionally, it calls on the EU to improve its monitoring of funds to ensure they support community integration rather than institutional care, with penalties for non-compliance.

In 2022, as the first step of its ongoing review process, the Committee on the Rights of Persons with Disabilities issued the <u>list of issues</u>, a request for a summary of measures taken by the EU to implement the previously made recommendations<sup>43</sup>. The Commission <u>report</u> consisting of the

<sup>42</sup> Committee on the Rights of Persons with Disabilities, 2015, Concluding observations on the initial report of the European Union: Committee on the Rights of Persons with Disabilities, United Nations. Available at: <a href="https://digitallibrary.un.org/record/812354?ln=en&v=pdf">https://digitallibrary.un.org/record/812354?ln=en&v=pdf</a>.

<sup>&</sup>lt;sup>43</sup> Committee on the Rights of Persons with Disabilities, 2022, *List of issues prior to submission of the second and third periodic reports of the European Union*, United Nations. Available at: <a href="https://documents.un.org/doc/undoc/gen/g22/323/63/pdf/g2232363.pdf">https://documents.un.org/doc/undoc/gen/g22/323/63/pdf/g2232363.pdf</a>.

EU reply to the list of issues was released in April 2023<sup>44</sup>.

The Commission, answering the UNCRPD's request of measures, states:

- On ensuring that persons with disabilities in institutions have access to prevention mechanisms and legal remedies in case of torture and other cruel, inhuman or degrading treatment or punishment (art. 15): that the <u>Victims' Rights Directive</u> aims to ensure justice to all crime victims, that the Charter of Fundamental Rights emphasises the inviolability of human dignity and prohibits inhumane treatment<sup>45</sup>. In addition, the Commission answers that the 2021-2027 cohesion policy includes horizontal enabling conditions to ensure compliance with the Charter and the UNCRPD, with strict measures against non-compliance.
- On living independently and being included in the community (art. 19): that the Commission supports deinstitutionalisation and independent living through the 2021-2027 shared management funds, whose legal framework includes horizontal enabling conditions that apply to all cohesion policy operations. The Commission also reiterated its support to member states in making progress towards deinstitutionalisation and steering investments towards family and community-based solutions. Some of the thematic enabling conditions for the current cohesion policy funds include measures for the shift from institutional to family- and community-based care, and the deinstitutionalisation of health and long-term care, with non-fulfilment of enabling conditions leading to expenditure reimbursement issues. However, in accordance to Regulation (EU) 2021/1058 on the European Regional Development Fund and on the Cohesion Fund and despite one of the specific objectives of the ERDF being to promote the transition from institutional to family and community-based care, the Commission specifies that "national authorities can in some cases use EU funding for residential care facilities, since investments in institutions are not prohibited by the applicable legal framework"46. The Commission added that, under the Recovery and Resilience Facility (RRF), the estimated cost of measures related to long-term care amounts to approximately €7.3 billion.
- On children with disabilities (art 7): that the <u>EU Strategy on the Rights of the Child</u> commits to addressing the needs of children with disabilities by promoting access to mainstream services, independent living, and quality alternative care<sup>47</sup>. It supports transitioning from institutional care to family- and community-based options. The <u>European Child Guarantee</u> urges Member States to submit national action plans, with a strong focus on children with disabilities<sup>48</sup>.
- On the respect for home and the family (art. 23): that the <u>European Care Strategy</u> aims to ensure quality, affordable, and accessible care services across the EU, focusing on

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European Commission, 2023, COMMISSION STAFF WORKING DOCUMENT Report on the Implementation of the UN Convention on the Rights of Persons with Disabilities (CRPD) by the European Union, European Council. Available at: <a href="https://data.consilium.europa.eu/doc/document/ST-8230-2023-INIT/en/pdf">https://data.consilium.europa.eu/doc/document/ST-8230-2023-INIT/en/pdf</a>.

<sup>&</sup>lt;sup>45</sup> European Parliament and the Council of the European Union, 2012, *Directive 2012/29/EU of 25 October 2012 establishing minimum standards on the rights, support and protection of victims of crime, and replacing Council Framework Decision 2001/220/JHA,* EUR-LEX. Available at: <a href="https://eur-lex.europa.eu/legal-content/EN/TXT/?qid=1421925131614&uri=CELEX:32012L0029">https://eur-lex.europa.eu/legal-content/EN/TXT/?qid=1421925131614&uri=CELEX:32012L0029</a>.

<sup>&</sup>lt;sup>46</sup> European Parliament and the Council of the European Union, 2021, *Regulation (EU) 2021/1058 of 24 June 2021 on the European Regional Development Fund and on the Cohesion Fund*, EUR-LEX. Available at: <a href="https://eur-lex.europa.eu/eli/reg/2021/1058/oj">https://eur-lex.europa.eu/eli/reg/2021/1058/oj</a>.

<sup>&</sup>lt;sup>47</sup> European Commission, 2021, EU strategy on the rights of the child, EUR-LEX. Available at: https://eur-lex.europa.eu/legal-content/en/TXT/?uri=CELEX%3A52021DC0142.

European Council, 2021, Council Recommendation (EU) 2021/1004 of 14 June 2021 establishing a European Child Guarantee, EUR-LEX. Available at: https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX%3A32021H1004.

improving the situation for both care recipients and caregivers<sup>49</sup>. It advocates for a person-centred approach to care and includes actions such as providing technical support for integrated care approaches and establishing strategic partnerships with the World Health Organisation (WHO) to enhance care quality. Additionally, the Council Recommendation on access to affordable high-quality long-term care offers guidance on developing sustainable care systems, ensuring better access to services for all, including persons with disabilities<sup>50</sup>. The recommendation calls on Member States to improve social protection for long-term care and increase the availability of services, with an emphasis on home and community-based care, closing territorial gaps, and respecting the right of persons with disabilities to live independently in the community. Furthermore, the EU Strategy on the Rights of the Child highlights the equal right of all children, including those with disabilities, to live with their families and in the community, urging Member States to accelerate deinstitutionalisation and transition to quality family- and community-based care<sup>51</sup>.

# 3.2. Main barriers to deinstitutionalisation and the right to independent living

The EU's Fundamental Rights Agency (FRA) found that despite commitments to deinstitutionalisation, significant gaps remain in achieving it practically<sup>52</sup>. Some of the issues participants of the study pointed to were limited stakeholder engagement, lack of clear timelines, inadequate funding (not only in overall levels but also in the accessibility and allocation of funds) and insufficient monitoring of national strategies as primary barriers. Similarly, findings from the European Network on Independent Living (ENIL) echo these concerns, with only 24 out of 43 Council of Europe countries having any form of deinstitutionalisation strategy, and, for the 18 countries that do, nearly 90% of respondents describing these existing strategies as either inadequate or in need of significant improvement<sup>53</sup>.

The European Association of Service providers for Persons with Disabilities (EASPD) emphasises that support services are essential for enabling people with disabilities to lead independent, meaningful lives within their communities<sup>54</sup>. These services range from personal care and home-based support to community participation, employment, and education assistance, all aiming to create ordinary life opportunities. However, the EASPD finds that outdated infrastructures, staff shortages, and increasing demand pose challenges. Current legal and fiscal policies fail to meet individuals' evolving needs, limiting access to community-based services and hindering the right to independent living.

European Commission, 2022, Commission communication on the European care strategy, EUR-LEX. Available at: <a href="https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX%3A52022DC0440">https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX%3A52022DC0440</a>.

<sup>&</sup>lt;sup>50</sup> Council of the European Union, 2022, *Recommendation of 8 December 2022 on access to affordable high-quality long-term care*, EUR-LEX. Available at: <a href="https://eur-lex.europa.eu/legal-content/en/TXT/?uri=CELEX%3A32022H1215%2801%29">https://eur-lex.europa.eu/legal-content/en/TXT/?uri=CELEX%3A32022H1215%2801%29</a>.

<sup>51</sup> European Commission, 2021, EU strategy on the rights of the child, EUR-LEX. Available at: https://eur-lex.europa.eu/legal-content/en/TXT/?uri=CELEX%3A52021DC0142.

<sup>&</sup>lt;sup>52</sup> European Union Agency for Fundamental Rights (FRA), 2018, *From institutions to community living for persons with disabilities:* perspectives from the ground, FRA. Available at: <a href="https://fra.europa.eu/sites/default/files/fra\_uploads/fra-2018-from-institutions-to-community-living-ground-perspectives\_en.pdf">https://fra.europa.eu/sites/default/files/fra\_uploads/fra-2018-from-institutions-to-community-living-ground-perspectives\_en.pdf</a>.

<sup>53</sup> Sanden. F., 2023, ENIL successfully shaped European Parliament resolution, ENIL. Available at: https://enil.eu/enil-successfully-shaped-european-parliament-resolution/.

European Association of Service providers for Persons with Disabilities (EASPD), 2022, Independent Living and Inclusion in the Community for Persons with Disabilities, EASPD. Available at:
<a href="https://easpd.eu/fileadmin/user\_upload/Publications/Independent\_Living\_and\_Inclusion\_in\_the\_Community\_Position\_Paper\_EASPD.pdf">https://easpd.eu/fileadmin/user\_upload/Publications/Independent\_Living\_and\_Inclusion\_in\_the\_Community\_Position\_Paper\_EASPD.pdf</a>.

The latest Eurofound report also states that the lack of funding directed towards relevant policies prevents Member States from establishing, and maintaining, adequate levels of family- and community-based care and services<sup>55</sup>. As a result, in the majority of Member States, the scale and adequacy of these services are reported to be insufficient for many of the population groups covered in this report.

Additionally, the shift to community-based care has led to increased reliance on informal caregiving, frequently by family members, who may face overwhelming physical, emotional, and financial pressures<sup>56</sup>. Without sufficient support, these conditions become unsustainable, underscoring the need for comprehensive resources and backing for families.

A successful transition toward deinstitutionalisation for persons with disabilities requires both physical and cultural shifts, according to the FRA<sup>57</sup>. This process involves moving away from institutional settings to accessible, community-based housing and adapting services to meet individual needs rather than applying uniform, one-size-fits-all solutions. However, as highlighted by Eurofound, persistent stigma and discrimination create significant obstacles to community-based care, often leading to social isolation, reluctance to seek support, and exclusion from opportunities in employment and housing<sup>58</sup>. Stigmatisation of those at risk of social exclusion fosters loneliness and prevents individuals from fully participating in society. The report also shows that an institutional culture can persist in any setting, including community-based alternatives. For deinstitutionalisation efforts to succeed, this institutional mindset must be addressed and transformed<sup>59</sup>. Simply transferring practices from institutional settings into the community risks reinforcing this culture. Therefore, family- and community-based care must be accompanied by a cultural shift among service providers. Effective policy implementation also requires empowering those affected by policies, ensuring their active involvement and that their voices are heard throughout the process.

The **continuous EU funding for institutions** (including group homes and nursing homes that do not respect articles 12, 14 and 19 of the UNCRPD) **is a barrier to advance deinstitutionalisation in the EU** for many organisations such as ENIL and the FRA. On this topic, the **European Ombudsman led an own-initiative inquiry** concerning how the **European Commission monitors that Member States use ESI funds to promote the right of persons with disabilities to independent living<sup>60</sup>.** 

Additionally, the European Network on Independent Living (ENIL) identifies that the EU-funded deinstitutionalisation process has, problematically, led to the creation of group homes and segregated settings rather than true independent living options as outlined in Article 19<sup>61</sup>.

<sup>&</sup>lt;sup>55</sup> Eurofound, 2024, *Paths towards independent living and social inclusion in Europe*, Publications Office of the European Union, Eurofound. Available at:

https://www.eurofound.europa.eu/en/publications/2024/paths-towards-independent-living-and-social-inclusion-europe.

European Union Agency for Fundamental Rights (FRA), 2018, From institutions to community living for persons with disabilities: perspectives from the ground, FRA. Available at: <a href="https://fra.europa.eu/sites/default/files/fra\_uploads/fra-2018-from-institutions-to-community-living-ground-perspectives\_en.pdf">https://fra.europa.eu/sites/default/files/fra\_uploads/fra-2018-from-institutions-to-community-living-ground-perspectives\_en.pdf</a>.

<sup>57</sup> Ibid.

<sup>58</sup> Ibid.

<sup>59</sup> Ibid.

<sup>&</sup>lt;sup>60</sup> European Ombudsman, 2022, How the European Commission monitors EU Structural and Investment funds to ensure they are used to promote the right of persons with disabilities to independent living and inclusion in the community, European Ombudsman. Available at: <a href="https://www.ombudsman.europa.eu/en/case/en/58464">https://www.ombudsman.europa.eu/en/case/en/58464</a>.

<sup>&</sup>lt;sup>61</sup> European Network for Independent Living (ENIL), 2022, *Shadow report on the implementation of the UN Convention on the Rights of Persons with Disabilities in the European Union*, EASPD. Available at:

Indeed, ENIL states that 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 (see Figure 4). Such arrangements often replicate institutional conditions—limiting personal choice, enforcing shared living and support arrangements, and creating "institutional" environments. ENIL emphasises the need to redirect funding toward individualised, community-based support and accessible housing options to prevent forced placement in residential care due to inadequate community support.

ENIL also highlights the **impact of COVID-19 on people with disabilities**, **who experienced increased restraints and high mortality rates in institutions**<sup>62</sup>. The pandemic highlighted the **increased levels of violence faced by persons with disabilities**. Indeed, people with disabilities, in particular women, the elderly and children, are at greater risk of suffering from violence and abuse, both at home and in care institutions: **17% of people with disabilities are victims of violence**, compared with 8% of people without disabilities<sup>63</sup>. According to the ENIL, many institutions (including group and nursing homes) "practice torture, including the use of cage beds and straightjackets, and deny basic healthcare"<sup>64</sup>. The UNCRPD Committee also, in article 2 of its *Guidelines on deinstitutionalization, including in emergencies*, states that COVID-19 "uncovered widespread institutionalization, highlighting the harmful impact of institutionalization on the rights and lives of persons with disabilities, and the violence, neglect, abuse, ill-treatment and torture, including chemical, mechanical and physical restraints, that they experience in institutions"<sup>65</sup>.

According to the European Disability Forum (EDF) and the FRA, persons with **psychosocial and intellectual disabilities are particularly affected by discriminatory laws and practices**<sup>66,67</sup>. The UNCRPD, in its 2015 observations also mentions this issue, "The Committee is concerned that across the European Union, persons with disabilities, **especially persons with intellectual and/or psychosocial disabilities still live in institutions rather than in their local communities"<sup>68</sup>. These inequities put them at <b>increased risk of forced treatment and involuntary placement** (whether without their consent or with consent provided by a substitute decision-maker) in psychiatric hospitals, institutions, or similar facilities, denying them of their legal capacity and the right to make informed choices about their own medical care, violating Article 14 of the UNCRPD.

https://easpd.eu/fileadmin/user\_upload/Publications/Independent\_Living\_and\_Inclusion\_in\_the\_Community\_Position\_Paper\_\_ \_EASPD.pdf.

<sup>&</sup>lt;sup>62</sup> European Network for Independent Living (ENIL), 2022, Shadow report on the implementation of the UN Convention on the Rights of Persons with Disabilities in the European Union, EASPD. Available at: <a href="https://easpd.eu/fileadmin/user-upload/Publications/Independent Living-and-Inclusion-in-the-Community-Position-Paper-EASPD.pdf">https://easpd.eu/fileadmin/user-upload/Publications/Independent Living-and-Inclusion-in-the-Community-Position-Paper-EASPD.pdf</a>.

<sup>&</sup>lt;sup>63</sup> European Council, 2024, *Disability in the EU: facts and figures, European Council.* Available at: https://www.consilium.europa.eu/en/infographics/disability-eu-facts-figures/.

European Network for Independent Living (ENIL), 2022, Shadow report on the implementation of the UN Convention on the Rights of Persons with Disabilities in the European Union, EASPD. Available at: <a href="https://easpd.eu/fileadmin/user\_upload/Publications/Independent\_Living\_and\_Inclusion\_in\_the\_Community\_Position\_Paper\_-\_EASPD.pdf">https://easpd.eu/fileadmin/user\_upload/Publications/Independent\_Living\_and\_Inclusion\_in\_the\_Community\_Position\_Paper\_-\_EASPD.pdf</a>.

Office of the High Commissioner for Human Rights, 2022, CRPD/C/5: Guidelines on deinstitutionalization, including in emergencies (2022), United Nations. Available at: <a href="https://www.ohchr.org/en/documents/legal-standards-and-guidelines/crpdc5-guidelines-deinstitutionalization-including">https://www.ohchr.org/en/documents/legal-standards-and-guidelines/crpdc5-guidelines-deinstitutionalization-including</a>.

<sup>&</sup>lt;sup>66</sup> European Disability Forum (EDF), 2024, European Human Rights Report - Legal capacity: Personal choice and control, EDF. Available at: https://www.edf-feph.org/content/uploads/2004/08/Human-Rights-Report-2024-Legal-Capacity-Final.pdf.

<sup>&</sup>lt;sup>67</sup> European Union Agency for Fundamental Rights (FRA), 2018, From institutions to community living for persons with disabilities: perspectives from the ground, FRA. Available at: <a href="https://fra.europa.eu/sites/default/files/fra\_uploads/fra-2018-from-institutions-to-community-living-ground-perspectives\_en.pdf">https://fra.europa.eu/sites/default/files/fra\_uploads/fra-2018-from-institutions-to-community-living-ground-perspectives\_en.pdf</a>.

<sup>68</sup> Committee on the Rights of Persons with Disabilities, 2015, Concluding observations on the initial report of the European Union: Committee on the Rights of Persons with Disabilities, United Nations. Available at: <a href="https://digitallibrary.un.org/record/812354?ln=en&v=pdf">https://digitallibrary.un.org/record/812354?ln=en&v=pdf</a>.

# 4. RECOMMENDATIONS AND WAY FORWARD

## **KEY FINDINGS**

EU agencies and key stakeholders' research indicates that policies towards the transition to community-based living for persons with disabilities should prioritise the involvement of people with care needs as well as coordination with third-sector organisations in decision-making processes. A person-centred approach, which offers individuals more choice and control over their care, is crucial, especially for those with complex needs. Successful deinstitutionalisation requires shifts in public attitudes to foster greater community acceptance, along with comprehensive national action plans that include clear goals and sufficient resources. Additionally, adequate housing, social inclusion, quality care and social services, and accessible public services are vital to support independent living.

Commissioner-designates have outlined their priorities for disability rights and independent living. Among these: new strategies towards deinstitutionalisation for 2026, the integration of disability issues into the EU Anti-Poverty Strategy, quality care services, the support of deinstitutionalisation through EU funding, and affordable housing for vulnerable groups, including those with disabilities. Additionally, the Commission has adopted guidance on independent living for persons with disabilities, providing practical recommendations to Member States on the use of EU funding to accelerate the transition from institutional care to community-based services and independent living. The Commission is also set to publish a Framework for Social Services of Excellence in O4 2024.

# 4.1. Recommendations from EU agencies and key stakeholders for advancing deinstitutionalisation and independent living

As for recommendations made by experts and researchers, Eurofound's latest report *Paths towards independent living and social inclusion in Europe* recommends **engaging people with care or support needs in the development and review of policies that affect them in order to ensure that their voices are heard<sup>69</sup>. The FRA also advises for <b>cooperation with third sector organisations and NGOs** in order to bring innovative ideas and experiences to the deinstitutionalisation process<sup>70</sup>.

A person-centred approach, which allows choice and control over family- and community-based care options, should be the foundation of these policies. The European Expert Group on Transition from Institutional to Community-Based Care, in its 2020 report, also calls for individualised support for all individuals, including those with complex needs<sup>71</sup>. FRA findings also point towards involving families of persons with disabilities throughout the deinstitutionalisation process. Support for exercising legal capacity and access to justice, as well as complaint mechanisms, are fundamental rights that must be safeguarded.

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<sup>&</sup>lt;sup>69</sup> Eurofound, 2024, *Paths towards independent living and social inclusion in Europe*, Publications Office of the European Union, Eurofound. Available at:

https://www.eurofound.europa.eu/en/publications/2024/paths-towards-independent-living-and-social-inclusion-europe.

<sup>&</sup>lt;sup>70</sup> European Union Agency for Fundamental Rights (FRA), 2018, From institutions to community living for persons with disabilities: perspectives from the ground, FRA. Available at:

 $<sup>\</sup>underline{https://fra.europa.eu/sites/default/files/fra\_uploads/fra-2018-from-institutions-to-community-living-ground-perspectives\_en.pdf.}$ 

<sup>&</sup>lt;sup>71</sup> Šiška. J and Beadle-Brown. J., (European Expert Group on Transition from Institutional to Community-Based Care), *Report on the transition from institutional care to community-based services in 27 EU Member States*, Inclusion Europe. Available at: <a href="https://www.inclusion-europe.eu/wp-content/uploads/2020/01/eeg-di-report-2020-1.pdf">https://www.inclusion-europe.eu/wp-content/uploads/2020/01/eeg-di-report-2020-1.pdf</a>.

A successful transition toward deinstitutionalisation for persons with disabilities requires changes in public attitudes according to the FRA<sup>72</sup>. Indeed, they state that shifts in public perceptions of individuals with disabilities are influenced by **deinstitutionalisation**, which fosters a "virtuous cycle". As people with disabilities gain greater visibility in the community, communities become more accepting, facilitating a smoother transition process.

For the Europe-wide network for persons with disabilities, ENIL, at national level, **EU Member States** need to implement adequate plans of action for deinstitutionalisation and the introduction of independent living<sup>73</sup>. In addition, ENIL adds that these plans have to contain specific objectives, fixed timeframes as well as the necessary resource commitments. Indeed, according to ENIL's 2020 survey, **24 out of the 43 countries represented in the Council of Europe lack a formal deinstitutionalisation strategy** altogether, and "for the **18 countries that do have one**, **88% of respondents have described the strategy as either inadequate or requiring improvement**"<sup>74</sup>.

Researchers also put forward increasing family- and community-based care alternatives, like kinship care, foster care, and adoption, as crucial for children needing placement<sup>75</sup>. Moreover, in nearly all EU countries, research showed a lack of affordable, community-based, and social housing, this, in turn, poses a significant barrier to expanding community living and tackling homelessness<sup>76</sup>. Effective housing policies, strategies, and practices are critical to sustaining deinstitutionalisation; under the condition housing provisions remain independent of care services to prevent institutional patterns.

In addition of housing, the Eurofound report highlights the need for **promotion of social inclusion** through **access to mainstream services—including employment**, **education**, **healthcare**, **transport**, **and public spaces—which need to be inclusive and readily accessible** to support full participation in society.

Eurofound also highlights the importance of **delivering quality support**, for which **sufficient staffing levels**, **fair wages**, **and strengthened** training for care and social service workers are critical. The FRA also highlights the role of staff (re-) training, recruitment and staff commitment to independent living in empowering people with disabilities to transition to the community and set a positive example for other staff members<sup>77</sup>. **Support for informal caregivers** is equally important, with access to respite care, leave, training, counselling, peer support, and financial and technological assistance to alleviate the strain on families.

The group on experts on the transition to community-based care, also identifies **responsibility** as a key issue. In many EU priority countries, **deinstitutionalisation efforts risk being seen as** 

<sup>&</sup>lt;sup>72</sup> European Union Agency for Fundamental Rights (FRA), 2018, *From institutions to community living for persons with disabilities:* perspectives from the ground, FRA. Available at: <a href="https://fra.europa.eu/sites/default/files/fra\_uploads/fra-2018-from-institutions-to-community-living-ground-perspectives\_en.pdf">https://fra.europa.eu/sites/default/files/fra\_uploads/fra-2018-from-institutions-to-community-living-ground-perspectives\_en.pdf</a>.

<sup>73</sup> Sanden. F., 2023, ENIL successfully shaped European Parliament resolution, ENIL. Available at: https://enil.eu/enil-successfully-shaped-european-parliament-resolution/.

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<sup>&</sup>lt;sup>75</sup> European Union Agency for Fundamental Rights (FRA), 2018, From institutions to community living for persons with disabilities: perspectives from the ground, FRA. Available at: <a href="https://fra.europa.eu/sites/default/files/fra\_uploads/fra-2018-from-institutions-to-community-living-ground-perspectives\_en.pdf">https://fra.europa.eu/sites/default/files/fra\_uploads/fra-2018-from-institutions-to-community-living-ground-perspectives\_en.pdf</a>.

<sup>56</sup> Šiška. J and Beadle-Brown. J., (European Expert Group on Transition from Institutional to Community-Based Care), Report on the transition from institutional care to community-based services in 27 EU Member States, Inclusion Europe. Available at: <a href="https://www.inclusion-europe.eu/wp-content/uploads/2020/01/eeg-di-report-2020-1.pdf">https://www.inclusion-europe.eu/wp-content/uploads/2020/01/eeg-di-report-2020-1.pdf</a>.

<sup>&</sup>lt;sup>77</sup> European Union Agency for Fundamental Rights (FRA), 2018, *From institutions to community living for persons with disabilities:* perspectives from the ground, FRA. Available at: <a href="https://fra.europa.eu/sites/default/files/fra\_uploads/fra-2018-from-institutions-to-community-living-ground-perspectives\_en.pdf">https://fra.europa.eu/sites/default/files/fra\_uploads/fra-2018-from-institutions-to-community-living-ground-perspectives\_en.pdf</a>.

temporary, "EU-funded projects," lacking the sustainability needed to extend results beyond EU funding<sup>78</sup>. Therefore, they advise for national deinstitutionalisation strategies to include sufficient funding, concrete implementation plans, and monitoring mechanisms to ensure sustainable progress. The FRA also identifies political commitment at the national and local level, backed up with adequate policies and implementation, as a key driver for successful deinstitutionalisation<sup>79</sup>. This cooperation at local level can take the form of formal working groups or networks, as well as rather informal networks.

The European Ombudsman led an own-initiative inquiry concerning how the European Commission monitors that Member States use ESI funds to promote the right of persons with disabilities to independent living<sup>80</sup>. The Ombudsman found that the Commission could enhance its guidance on promoting deinstitutionalisation within the use of ESI funds. She also suggested that the Commission should strengthen monitoring of ESI-funded activities and take a more proactive stance in enforcement, particularly when concerns arise about ESI-funded projects that may conflict with the goal of promoting deinstitutionalisation. The Ombudsman concluded that the Commission could offer clearer guidance on the need to promote deinstitutionalisation in the context of using ESI funds<sup>81</sup>. Additionally, she suggested that the Commission could enhance its monitoring of ESI-funded activities and adopt a more proactive approach to enforcement, especially when concerns arise that ESI-funded projects may conflict with the obligation to support deinstitutionalisation.

Since the adoption of the convention, ENIL has been collecting data on breaches of the obligation not to spend EU funding on institutions<sup>82</sup>. Their report shows that in many countries, despite the prohibition of using public or private funds to maintain institutions, the proliferation of group homes for people with disabilities in the EU has been supported with resources from ESI Funds (for example in Austria, Bulgaria, Croatia, the Czech Republic, Estonia, Greece, Hungary, Lithuania, Malta, Poland, Portugal, Romania and Slovenia)83. According to the organisation, the Ombudsman's inquiry highlighted that the European Commission's approach to allowing investments in institutions, provided these are justified as transitional measures, risks interpreting the legal framework too loosely84.

Both ENIL's experience and the Ombudsman's findings indicate a need for the European Commission to adopt stronger procedures to ensure that EU funds are used consistently with deinstitutionalisation objectives. Given the barriers persons with disabilities face in accessing justice, relying on individuals to take legal action against governments for misuse of funds is highly

<sup>78</sup> Šiška. J and Beadle-Brown. J., (European Expert Group on Transition from Institutional to Community-Based Care), Report on the transition from institutional care to community-based services in 27 EU Member States, Inclusion Europe. Available at: https://www.inclusion-europe.eu/wp-content/uploads/2020/01/eeg-di-report-2020-1.pdf.

<sup>&</sup>lt;sup>79</sup> European Union Agency for Fundamental Rights (FRA), 2018, From institutions to community living for persons with disabilities: perspectives from the ground, FRA. Available at: https://fra.europa.eu/sites/default/files/fra\_uploads/fra-2018-from-institutions-to-community-living-ground-perspectives\_en.pdf.

<sup>&</sup>lt;sup>80</sup> European Ombudsman, 2022, How the European Commission monitors EU Structural and Investment funds to ensure they are used to

promote the right of persons with disabilities to independent living and inclusion in the community, European Ombudsman. Available at: https://www.ombudsman.europa.eu/en/case/en/58464.

<sup>82</sup> European Network for Independent Living (ENIL), 2022, Shadow report on the implementation of the UN Convention on the Rights of Persons with Disabilities in the European Union, EASPD, Available at: https://easpd.eu/fileadmin/user\_upload/Publications/Independent\_Living\_and\_Inclusion\_in\_the\_Community\_Position\_Paper\_-EASPD.pdf.

<sup>83</sup> Ibid.

European Network for Independent Living (ENIL), 2022, Stopping the use of EU funds to support institutionalisation and segregation, ENIL. Available at: https://enil.eu/stopping-the-use-of-eu-funds-to-support-institutionalisation-and-segregation/.

inadequate according to ENIL<sup>85</sup>.

Lastly, research suggests collecting and analysing EU-wide data on care provision, disaggregated by factors such as age and gender, as well as data on people's lived experiences regarding choice, control, inclusion, and participation, the latter being essential for tracking living conditions, policy effectiveness and impact at the individual level, and trends<sup>86,87</sup>. For instance, ENIL recommends the EU to collect information on the number of people with disabilities living in institutions<sup>88</sup>.

# 4.2. 2024-2029 Commissioner-designates portfolios and commitments

As the EU is in the process of designating the future commissioners for the next five years, it is essential to analyse the commissioner-designates' stance on issues related to persons with disabilities and independent living.

According to the written questionnaires, Commissioner-designates with the themes of poverty, affordable housing and persons with disabilities within their portfolio, made the following statements:



**Hadja Lahbib** 

**Portfolio:** Commissioner for Preparedness and Crisis Management; Equality

## More information

- Biography
- Mission letter to Hadja Lahbib

Commissioner-designate Hadja Lahbib has emphasised her strong commitment to **prioritising negotiations on the Equal Treatment Directive**, aiming to ensure comprehensive equality protections. She intends to closely oversee the **implementation of two newly adopted Directives aimed at strengthening equality bodies that provide support to victims of discrimination**.

With the next report on the Racial Equality and Employment Equality Directives scheduled for 2026, she has proposed a particular focus on sanctions in cases of discrimination. Lahbib also plans to address issues of hate speech and hate crimes, with a special focus on persons with disabilities.

European Network for Independent Living (ENIL), 2022, Shadow report on the implementation of the UN Convention on the Rights of Persons with Disabilities in the European Union, EASPD. Available at:

https://easpd.eu/fileadmin/user\_upload/Publications/Independent\_Living\_and\_Inclusion\_in\_the\_Community\_Position\_Paper\_-\_\_EASPD.pdf.

<sup>&</sup>lt;sup>86</sup> Eurofound, 2024, *Paths towards independent living and social inclusion in Europe*, Publications Office of the European Union, Eurofound. Available at:

 $<sup>\</sup>underline{https://www.eurofound.europa.eu/en/publications/2024/paths-towards-independent-living-and-social-inclusion-europe.}$ 

<sup>87</sup> Šiška. J and Beadle-Brown. J., (European Expert Group on Transition from Institutional to Community-Based Care), Report on the transition from institutional care to community-based services in 27 EU Member States, Inclusion Europe. Available at: https://www.inclusion-europe.eu/wp-content/uploads/2020/01/eeg-di-report-2020-1.pdf.

<sup>88</sup> Sanden. F., 2023, ENIL successfully shaped European Parliament resolution, ENIL. Available at: https://enil.eu/enil-successfully-shaped-european-parliament-resolution/.

On the matter of equality data, Lahbib **proposes that the Commission will intensify its efforts in gathering and improving equality statistics**, aligning with renewed equality strategies. If confirmed, she aims to collaborate extensively with Member States, the EU Fundamental Rights Agency (FRA), the European Institute for Gender Equality (EIGE), Council Presidencies, the UN Praia Group, civil society, and other stakeholders to **enhance equality data quality and scope**.

The Commission is currently preparing a progress report on the Strategy for the Rights of Persons with Disabilities 2021-2030, assessing its implementation and addressing any remaining challenges. As the EU's focal point under the UN Convention on the Rights of Persons with Disabilities, the Commission is also gearing up for constructive dialogue on the Convention's implementation within the EU. This ongoing work is essential for identifying remaining gaps and, if necessary, updating the Strategy's objectives and actions. Lahbib has committed to ensuring that the Commission follows Member States' progress towards accession to the UNCRPD's Optional Protocol, noting that the proposal for EU accession to the Protocol has awaited Council action since 2008.

Should she be confirmed, one of her early priorities will be to close these gaps and advance a Europe without barriers for persons with disabilities, focusing on employment, independent living, accessibility, and the integration of disability considerations across all policy areas.

In relation to the Equality Taskforce, **Lahbib will work across relevant strategies to propose measures for individuals facing discrimination**, including marginalised groups such as persons with disabilities.

She intends to work closely with the Executive Vice-President for People, Skills and Preparedness, who will introduce a new Action Plan for implementing the European Pillar of Social Rights and an EU Anti-Poverty Strategy, as well as with the Commissioner for Energy and Housing, who will propose the first-ever European Affordable Housing Plan.

**During her confirmation hearing**, on 6 November 2024, Lahbib said the following:

"An important initiative that I see is deinstitutionalisation: getting disabled people out of institutions, to allow them to lead the lives they want, where they want and when they want. So we will have to change our mindset a little. I know that there are very strong institutions in many countries, but this goes against the empowerment of disabled people. I will therefore ensure that we develop the right strategies with representatives on the ground and with the equality centers, which will be strengthened from 2026 and which will also be able to give a voice to these people with disabilities. Another initiative to enable deinstitutionalization: we need better support at the social level for disabled people<sup>89</sup>."

European Parliament, 2024, Hearing of Hadja Lahbib. Available at: https://hearings.elections.europa.eu/documents/lahbib/verbatimreporthearing-original.pdf.



## Roxana Mînzatu

**Portfolio:** Executive Vice-President for People, Skills and Preparedness

More information

- Biography
- Mission letter to Roxana Mînzatu

As Minister or Secretary of State, Ms Minzatu coordinated Romania's initiatives under the European Social Fund, focusing on policies and reforms aimed at improving the lives of marginalised groups, particularly people with disabilities. Her efforts included systemic reforms in public procurement and legislation designed to promote their integration into the labour market.

Regarding housing, she plans to support the work of the Commissioner for Energy and Housing in advancing the European Affordable Housing Plan. She is committed to ensuring that this plan includes a strong social dimension that addresses the needs of vulnerable populations, including individuals with disabilities and those experiencing homelessness, utilising the housing-first principle as a fundamental approach.

If confirmed as Executive Vice-President, she will focus on developing the EU Anti-Poverty Strategy to effectively support the most disadvantaged in society and combat social inequalities. Addressing the root causes of poverty—such as discrimination, social injustice, and inadequate access to essential services—will be a priority, particularly for individuals with disabilities.

Ms Minzatu recognises that social exclusion often stems from systemic discrimination and inequalities. She intends to integrate these issues into the Strategy and align her efforts with the goal of achieving a Union of Equality. Her focus will include **enhancing access to quality, affordable care for families and creating quality jobs for caregivers**.

Upon confirmation as Executive Vice-President, she will engage with the European Semester concerning social, education, and employment policies, ensuring a strong social dimension remains at its core. Building on the European Social Fund Plus (ESF+), which underpins the European Pillar of Social Rights and aims to reduce poverty and social exclusion, she will collaborate with fellow Commissioners to develop comprehensive policies and funding solutions. The work led by the Commissioner for Energy and Housing on the European Affordable Housing Plan and the Action Plan for Affordable Energy Prices will be crucial in ensuring these initiatives effectively support vulnerable groups, including those with disabilities.

Looking ahead, the next **Multiannual Financial Framework** presents an opportunity for more focused, streamlined, and impactful spending. Ms Minzatu aims to link investments with reforms to address challenges in education, skills, and poverty alleviation.

In line with the active inclusion paradigm, she plans to prioritise issues such as low incomes and barriers to accessing the labour market and essential services, including energy and transport.

Recognising the disproportionate burden of caring responsibilities on women, Ms Minzatu will advocate for **high-quality**, **affordable**, **and accessible care services across the EU** to enhance women's participation in the labour market throughout their lives. She is committed to **intensifying efforts to implement the European Care Strategy**, **particularly focusing on the Council Recommendations related to early childhood education and long-term care**.



**Raffaele Fitto** 

**Portfolio:** Executive Vice-President for Cohesion and Reforms

More information

- Biography
- Mission letter to Raffaele Fitto

Commissioner-designate Raffaele Fitto has pledged to **reinforce the social dimension of cohesion policy, guided by the European Pillar of Social Rights** to advance the commitments outlined in his mission letter. Building on the solid foundations set in the current 2021-2027 programming period, the ESF+ plays a key role in **enhancing both accessibility and the quality of social services** across EU regions, with a **particular focus on vulnerable groups and persons with disabilities**.

Looking forward, he will work with the Commissioner for Preparedness, Crisis Management, and Equality, to improve accessibility and services specifically tailored for persons with disabilities. Fitto affirms the Union's role in supporting the right of persons with disabilities to live independently and be fully included in the community. EU funds, he notes, are essential in advancing this goal by aiding in the process of deinstitutionalisation across Member States.



Dan Jørgensen

Portfolio: Commissioner for Energy and Housing

More information

- Biography
- Mission letter to Dan Jørgensen

Commissioner-designate Dan Jørgensen has **committed to introducing the European Commission's first-ever European Affordable Housing Plan**, aligning with his Mission Letter. This plan will provide technical assistance to cities and Member States, foster investments, and emphasise the skills required within the housing sector. Additionally, the Plan will include a targeted strategy to boost housing supply, especially in areas with pressing housing needs.

Under the direction of the Executive Vice-President for People, Skills and Preparedness, the Commission is set to launch the EU's inaugural Anti-Poverty Strategy. **Jørgensen has pledged to** 

work closely with the Executive Vice-President to maximise synergies between the European Affordable Housing Plan and the EU Anti-Poverty Strategy.

In line with commitments established in the Energy Performance of Buildings Directive and the Energy Efficiency Directive, Jørgensen will prioritise national financial incentives for vulnerable households, including those impacted by energy poverty and those residing in social housing. Additionally, he plans to collaborate with diverse stakeholders to address energy poverty and support the long-term development of green, social, and public housing across the EU.

# 4.3. Upcoming research and legislation

Beginning in December 2023, the **FRA** has started a research project on <u>Fundamental rights</u> <u>protection of persons with disabilities in institutions</u><sup>90</sup>. This project will explore how <u>duty-bearers</u> work to prevent and respond to incidents of violence and abuse against persons with <u>disabilities in institutional settings</u>. It complements the FRA's role within the EU Framework for the UNCRPD, and enhances the Agency's ongoing work in supporting victims' rights.

The <u>Directive on adequate minimum wages</u> in the European Union, adopted in 2022, acknowledged that **people with disabilities are more likely to be minimum or low-wage earners compared to other groups**<sup>91</sup>. During economic downturns, like the COVID-19 crisis, minimum wages play a crucial role in protecting low-wage workers and are essential for promoting a sustainable and inclusive economic recovery. **EU Member States are required to comply with the Directive by 15 November 2024**.

Under the European Strategy on the Rights of Persons with Disabilities, the European Commission has recently adopted guidance on independent living for persons with disabilities<sup>92</sup>. Its purpose is to provide practical recommendations to Member States towards the realisation of the right to independent living and inclusion in the community in the context of EU funding in line with Article 19 of the UNCRPD and applicable Union law.

Additionally, the Commission is programmed to release a **Framework for Social Services of Excellence to improve the quality of community-based services**, for 2024 also.

Lastly, at her confirmation hearing, Commissioner-designate Ms. Lahbib emphasized the importance of deinstitutionalisation, stating that it is crucial to enable people with disabilities to have agency and freedom of choice over their lives<sup>93</sup>. To support this, **she committed to developing the right strategies in collaboration with local representatives and equality centres, which will be strengthened from 2026 to give a stronger voice to persons with disabilities.** Furthermore, Ms. Lahbib highlighted another initiative towards the transition to deinstitutionalisation; better support at the social level for people with disabilities.

<sup>&</sup>lt;sup>90</sup> European Union Agency for Fundamental Rights (FRA), 2018, Fundamental rights protection of persons with disabilities in institutions, FRA. Available at: <a href="https://fra.europa.eu/en/project/2024/fundamental-rights-protection-persons-disabilities-institutions">https://fra.europa.eu/en/project/2024/fundamental-rights-protection-persons-disabilities-institutions</a>.

<sup>&</sup>lt;sup>91</sup> European Parliament, 2022, Directive (EU) 2022/2041 of the European Parliament and of the Council of 19 October 2022 on adequate minimum wages in the European Union, EUR-LEX. Available at: <a href="https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX%3A32022L2041&qid=1729519172780">https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX%3A32022L2041&qid=1729519172780</a>.

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<sup>&</sup>lt;sup>93</sup> European Parliament, 2024, Hearing of Hadja Lahbib. Available at: https://hearings.elections.europa.eu/documents/lahbib/verbatimreporthearing-original.pdf.

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The right to independent living and community inclusion for the EU's 101 million citizens with disabilities is enshrined in Article 19 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and is further supported by the EU Disability Strategy 2021–2030. This analysis provides a comprehensive overview of the current landscape, ongoing challenges, key stakeholder recommendations, and future political perspectives regarding independent living and deinstitutionalisation.

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