

EPR Briefing

Guidance on Independent Living: one year after publication

Introduction

This Briefing aims to help readers navigate the “Guidance on independent living and inclusion in the community of persons with disabilities in the context of EU funding” (hereafter referred to as the Guidance), a document published by the European Commission to support the realisation of the right of independent living and inclusion in the community in the context of EU funding, in line with Art. 19 of the UN Convention on the Rights of Persons with Disabilities (UNCRPD). This Briefing also aims to further support its dissemination and implementation. The European Platform for Rehabilitation (EPR) actively contributed to the discussions and exchanges for its development through the Disability Platform over 2024¹. The Briefing firstly presents the context under which the Guidance was drafted and published. Then, it provides an analysis of its content. Finally, the Briefing describes the next steps for the implementation of the guidance one year after its publication.

Context: The Guidance on Independent Living

The Guidance² is **a flagship initiative of the European Strategy on the Rights of Persons with Disabilities 2021-2030**³ (hereafter referred to as the Disability Strategy) and was published on 20 November 2024.

This Guidance was developed **in consultation with civil society organisations** with the aim of preventing EU funding from supporting segregation. Notably, it acknowledges the vital role played by social services in promoting independent living of persons with disabilities, and places focus on choice and a person- centred approach to care.

The Guidance **is interlinked with other Flagship initiatives of the Disability Strategy** such as the Framework on Social Services of Excellence for persons with disabilities, set to improve service delivery to persons with disabilities and upgrade of service providers’ skills to increase attractiveness of the sector.

This Guidance is built on **the principles of non-discrimination and equality**, enshrined in Articles 10 and 19 of the Treaty on the Functioning of the European Union⁴ on combatting discrimination. It aligns with the European Pillar of Social Rights⁵, concretely its Principle 17 on the inclusion of people with disabilities, and Article 19 of the UN Convention for the Rights of Persons with Disabilities

¹ The Guidance was developed in consultation with the [Disability Platform](#), which establishes close cooperation between Member States’ institutions, the European Commission and civil society on issues relating to disability, and facilitates the exchange of information, experiences and good practices.

² European Commission: Directorate-General for Employment, Social Affairs and Inclusion, *Guidance on Independent Living and Inclusion in the Community*, 2024, available [here](#).

³ European Commission: Directorate-General for Employment, Social Affairs and Inclusion, *Union of equality – Strategy for the rights of persons with disabilities 2021-2030*, Publications Office, 2021, available [here](#).

⁴ *Treaty of the functioning of the European Union*, 2012, available [here](#).

⁵ European Commission: Directorate-General for Employment, Social Affairs and Inclusion, *European Pillar of Social Rights Action Plan*, 2021, available [here](#).

(UNCRPD)⁶ on living independently and being included in the community. It also complements other initiatives, such as the European Care Strategy⁷ and its outputs: the Council Recommendation on access to affordable high-quality long-term care, and the Council recommendation on early childhood education and care (ECEC), as well as the Commission Communication on a comprehensive approach to Mental Health⁸.

A content analysis of the Guidance

Objective

The Guidance aims to suggest ways in which EU funding may promote the right of persons with disabilities to independent living and inclusion in the community.

However, the Guidance does not introduce any new criteria or mechanisms for the ongoing 2021-2027 funding period and does not create any additional legal obligations for the EU Member States.

Target audience

The Guidance is targeted to the bodies in charge of implementing EU funds (including the European Commission, national authorities like ministries and public institutions, and partner organisations such as international organisations like UN or the World Bank), as well as stakeholders that implement EU funded projects related to independent living activities, such as civil society, service providers, the academic community, and persons with disabilities and their families.

Independent Living and de-institutionalisation framework

The Guidance explains that, as per UN General Comment 5 on Living Independently⁹, **independent living provides persons with disabilities with all necessary means to exercise choice and control over all decisions concerning their lives** while being included in and able to interact with the community. It does not mean living and doing everything alone and getting by without support.

To enable independent living, places of residence must not be segregated or isolated from the local community. On the contrary, they must:

- Be placed within the community and there must be access to in-home and community-based services and support, as well as services available to the general population.
- Respect the freedom of choice of persons with disabilities over where and with whom to live and from whom to receive assistance
- Facilitate inclusion and participation in the community.
- Enable self-determination over day-to-day decisions.

Ensuring independent living requires a paradigm shift from a medical model of care for persons with disabilities to human rights approaches applying a social model for inclusion, participation and person-centeredness. Advancing in ensuring independent living therefore implies the re-direction of funds from institutional settings and services to accessible and non-segregated places of residence, community-based services and support.

⁶ United Nations, *Convention on the Rights of Persons with Disabilities*, 2006, available [here](#).

⁷ European Commission, *European Care Strategy Communication*, 2022, available [here](#).

⁸ European Commission, *Communication on a Comprehensive Approach to Mental Health*, 2023, available [here](#).

⁹ United Nations Committee on the Rights of Persons with Disabilities, *General comment No. 5 (2017) on living independently and being included in the community*, 2017, available [here](#).

The Guidance therefore proposes the structure of a **strategic framework** that can be used to achieve de-institutionalisation, which includes:

- a) A timeline for the overall deinstitutionalisation process.
- b) A needs-based analysis of investment gaps based on the individual needs of existing and potential service users, and mapping existing infrastructure, services and workforce.
- c) Targets that must be fulfilled within a specific timeframe and respective indicators.
- d) A dedicated budget and resources for the elaboration and implementation of individual plans, for the transition to independent living.
- e) A clear division of responsibilities among the main stakeholders implementing the actions, and clear governance.
- f) A robust and independent quality control system, incl. complaint mechanisms for persons with disabilities.
- g) Monitoring tools to guide the structural reforms.

Key independent living building blocks for EU funds investment

Preventing institutionalisation

Ensuring independent living for persons with disabilities requires efforts to prevent their institutionalisation in the first place. It is therefore key to consider the specificities of different groups to ensure their independent living and inclusion in the community, including children and young persons with disabilities, older persons with disabilities, women and girls with disabilities, as well as persons with disabilities from a racial and ethnic minority, and LGBTIQ persons with disabilities, adults with mental health problems, psychosocial disabilities and intellectual disabilities, persons with disabilities living in rural or remote areas, and persons with disabilities at risk of homelessness and poverty when leaving institutions. Affordable assistive technology and innovative technological solutions, and affordable non-segregated housing are also fundamental to prevent institutionalisation.

Person-centred approaches for independent living

Person-centred approaches safeguard that persons with disabilities can choose and control who is supporting them and receive a tailored support. Such services include personal assistance, in all aspects of persons with disabilities' lives (incl. at home, work, social and leisure activities), professional home care, including medical and non-medical support (e.g. cooking, cleaning), training to empower them to reach a maximum level of independence and self-sufficiency, and outreach, to ensure that information about programmes reach their intended users. Person-centred funding models/ personal budgets can facilitate tailoring funding to individual needs in a way that persons with disabilities and their families can arrange their own support.

Ensuring inclusion in the community

Services for the general population (incl. social and healthcare services, ECEC, education, training, employment, culture, leisure) must be available, accessible, inclusive and adaptable for persons with disabilities to ensure inclusion in the community. Establishing organised networks such as peer support groups or counselling centres for independent living are also key for inclusion in the community. Equally important for independent living is the development of labour market opportunities for persons with disabilities to secure their income (incl. through work trainers, reasonable accommodation, and co-worker trainings). These actions should be complemented by awareness-raising on the rights of persons with disabilities to change mindsets.

Enabling the transformation in service provision

To address effectively the needs of persons with disabilities through a person-centred approach, services must comply with quality requirements that consider their lived experience and guarantee self-determination, free choice and independent living. Quality assurance frameworks are accountability mechanisms across the EU that can contribute to improving persons' lived experience. To ensure quality services, it is key to build a skilled and sufficient workforce and improve the attractiveness of the sector of services for persons with disabilities by ensuring fair working conditions. Policies must promote training and support inclusive education to provide disability awareness and sensitivity among staff in the sector¹⁰.

Consultation and Participation

According to UNCRPD Article 4(3), signatory countries must consult and involve persons with disabilities in the development and implementation of policies promoting their rights. Therefore, it is key to consult persons with disabilities in decision-making processes supporting deinstitutionalisation and the transition towards community life, ensuring that information is provided in accessible formats and appropriate outreach. Moreover, the European Commission aims to maintain a partnership with relevant stakeholders, including service providers, in the implementation of EU funding.

Examples of activities that could be supported by EU funds to foster independent living

Area of support	Examples
Comprehensive national strategies to support independent living and deinstitutionalisation	Preparation of de-institutionalisation strategic frameworks: Analysis and consultations with stakeholders, data collection systems on persons in institutions and at home in need of care; capacity building for the preparation of the strategic framework; implementation and monitoring.
Preventing Institutionalisation	Provision of individual accessible social housing & home support; improving access to non-segregated housing and essential services; preventing institutionalisation tailored to the needs of different target groups; help support inclusion during crises and rapid response efforts.
Person-centred approaches for independent living	Developing a network of person-centered community-based services; accessible infrastructure, products, services, & assistive technologies and services; measures addressing carers' needs; personal budgets introduction and piloting; support for employment, incl. accessibility and reasonable accommodation.
Ensuring inclusion in the community	Improving access to mainstream social services; increase access to all levels of education and training; supporting the enrolment of children with disabilities in mainstream ECEC alongside children without disabilities; increasing access to e-services, promoting the e-inclusion of persons with disabilities; making social, health, employment housing, culture, & education and training infrastructure accessible; development of accessible transport.

¹⁰ A range of programs and support has been developed by the EU to assist Member States and service providers in training and recruiting high-quality staff, including: (i) a partnership for skills for the long-term care sector (available [here](#)); and (ii) a toolkit on the use of European Social Fund+ funds to train staff involved in independent living (available [here](#)).

Enabling the transformation in service provision	Training public authorities, healthcare, social & support services staff on independent living; developing curricula for jobs in community-based services; developing training & equipment to develop assistive tech and services; developing, piloting and implementing quality assurance mechanisms.
Consultation and participation	Involving civil society, independent fundamental rights bodies & organisations representing persons with disabilities in the design, implementation, monitoring and evaluation of the programmes and strategic frameworks.

Monitoring de-institutionalisation

In this section, the Guidance calls for the monitoring of progress towards de-institutionalisation of persons with disabilities in order to (i) support the implementation of the long-term strategic framework in place and (ii) inform policy development at national, regional and local level. Moreover, monitoring requires, improved data collection systems in terms of coverage (e.g. the number and living situation of persons with disabilities in institutions), disaggregation (by age, gender and disability type) and trend. EU sources, such as Eurostat and the European Health Interview Survey, are working to include data on persons living in institutions.

Self-Assessment Tool

In an annex, the Guidance proposes a tool for stakeholders to evaluate if projects and operators under EU funding align with the approaches described in the Guidance. It includes

- **General questions** – to assess if the rights of persons with disabilities are respected by the project, as well as if the project includes a strategic framework on Independent Living.
- **Conceptual questions** – to assess if the project uses the UNCRPD definition of persons with disabilities, if service providers are trained and knowledgeable on the human rights of persons with disabilities, if the operation affects the right to independent living of persons with disabilities, and if it avoids their abuse or violence and discrimination.
- **Independent living and inclusion in the community questions** – to assess the project's infrastructure (e.g. is there spatial segregation? Can persons easily reach and move within the community? Is it accessible?); its support services for persons with disabilities (e.g. if persons with disabilities have a say on the services they receive); if persons benefitting from the initiative are able to choose their place of residence, live with whom they want, move freely, and have control of their day-to-day life decisions; if the project demonstrates how persons with disabilities will remain in or return to the community.
- **Consultation questions** – questions regarding the involvement of persons with disabilities and their representative organisations in the project.

Guidance on Independent Living: Next Steps

Published in November 2024, the Guidance was conceived as a practical instrument providing orientations for policies and investments for independent living and aimed at all intervening stakeholders, focusing on use of EU funds. However, the guidance and its annex do not present any new binding requirements for Member States or stakeholders. It is merely a voluntary tool.

This is why; in order to increase the uptake of the Guidance, this publication is now in the dissemination phase among all relevant levels and actors involved. The upcoming proposal of new actions under Disability Strategy (2021-2030) might include tools supporting the Guidance's implementation.

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