

EUROPEAN COMMISSION

> Brussels, 20.11.2024 C(2024) 7897 final

COMMISSION NOTICE

Guidance on independent living and inclusion in the community of persons with disabilities in the context of EU funding

COMMISSION NOTICE

Guidance on independent living and inclusion in the community of persons with disabilities in the context of EU funding

This notice is intended purely as a guidance document to support 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 United Nations Convention on the Rights of Persons with Disabilities and applicable Union law.

This notice does not create any rights and obligations beyond those provided for in the legal framework. Only the Court of Justice of the European Union is competent to authoritatively interpret Union law.

1. BACKGROUND

The European Strategy for the Rights of Persons with Disabilities $2021-2030^1$ ('the Strategy') aims to improve the lives of persons with disabilities in the European Union (EU) and beyond, and promote their full participation in society, on an equal basis with others. The Strategy builds on the principles of equality and non-discrimination, cornerstones of EU policy, enshrined in the Treaty on the Functioning of the EU (TFEU) and the Charter of Fundamental Rights of the EU² ('the Charter'). The European Pillar of Social Rights³, in particular principle 17 on the inclusion of persons with disabilities, along with its related Action Plan⁴, also pursue the objective of achieving full inclusion and respect for the rights of persons with disabilities and contribute to achieving independent living and inclusion in the community for persons with disabilities.

The right to independent living for persons with disabilities is enshrined in **Article 19** of the **UN Convention on the Rights of Persons with Disabilities (UNCRPD)**⁵, to which the EU and its 27 Member States are Parties. The UNCRPD is an integral part of the legal order⁶ of the EU. Parties to the Convention must take measures to facilitate full enjoyment by persons with disabilities of the right to independent living 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

¹ Commission Communication (COM (2021) 101 final): <u>Union of Equality: Strategy for the Rights of</u> <u>Persons with Disabilities 2021-2030</u>.

² In particular: (i) the <u>Treaty on the Functioning of the European Union</u> and its Articles 10 and 19 on combatting discrimination based on disability; and (ii) the <u>Charter of Fundamental Rights of the European Union</u> and its Article 26 on the right of persons with disabilities to benefit from measures designed to ensure their independence, social and occupational integration, and participation in the life of the community.

³ European Pillar of Social Rights: <u>https://ec.europa.eu/social/main.jsp?catId=1606&langId=en</u>

⁴ European Pillar of Social Rights Action Plan: <u>https://ec.europa.eu/social/main.jsp?catId=1607&langId=en</u>

⁵ United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (un.org).

⁶ Pursuant to Article 216(2) TFEU, agreements concluded by the Union are binding upon the institutions of the Union and on its Member States. According to the Court of Justice Council Directive 2000/78/EC is indeed to be read in light of the UNCRPD and the Charter, see for instance the judgements in cases Ca Na Negreta (<u>C-631/22</u>, ECLI:EU:C:2024:53) and AP Assistenzprofis (<u>C-518/22</u>, ECLI:EU:C:2023:956)

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.⁷

Central to the right to independent living is therefore the individual choice of the place of residence, regardless of the disability, on an equal basis with others in society, and being able to decide one's living arrangements according to one's preferences.

In addition, independent living and inclusion in the community require the provision of community support services for persons with disabilities, including personal assistance, as well as access to community services and facilities for the general population.

Despite progress achieved so far, Member States are at different stages in developing the conditions for independent living and many persons with disabilities still live in institutions in the EU. Estimates suggest that there are more than 1 million persons with disabilities aged under 65 and more than 2 million aged 65+ living in institutions in the EU 27^8 .

Promoting independent living and the transition from institutional care to independent living and inclusion in the community, a process referred to as "deinstitutionalisation", and supporting Member States' efforts in this path has been a priority for the EU since it ratified the UNCRPD⁹. In the European Union, EU funds and commitment at national level have made significant contributions to advancing independent living for persons with disabilities in past programming periods. EU funds continue to support Member States' strategies and plans for the transition from institutional care to community-based services and independent living. Research shows that EU funds have been pivotal in starting the process of deinstitutionalisation in a number of countries.

Building on the good practices put in place so far, the present notice seeks to provide practical guidance on the use of EU funding to promote the realisation of the right of persons with disabilities to independent living and inclusion in the community.

This notice aims to illustrate how to apply in practice the approaches promoted in the regulations governing EU funds and does not introduce new or retroactive criteria or conditions for the 2021-2027 funding period. It does not create any additional legal obligations for the Member States. The approach presented in this notice is relevant to all EU funding instruments within their scope of support, including EU's external action and EU-funded projects internationally.

⁷ Over the years, the United Nations Committee on the Rights of Persons with Disabilities (CRPD Committee) has provided extensive interpretation of Article 19 of the Convention, notably in its 2017 General Comment No. 5 on living independently and being included in the community and the more recent 2022 Guidelines on deinstitutionalization, including in emergencies. These are non-legally binding documents that present the guidance of the CRPD Committee with the aim of steering Parties towards giving effect to the right of persons with disabilities to live independently and be included in the community.

⁸ Grammenos, S., *COVID-19 and persons with disabilities – Statistics on health, care, isolation and networking*, Publications Office of the European Union, 2021, <u>https://data.europa.eu/doi/10.2767/25503</u>.

⁹ – European Commission (2010), European Disability Strategy 2010–2020: A Renewed Commitment to a Barrier-Free Europe, COM (2010) 0636 final.

This notice offers guidance that is targeted at EU funds implementing bodies at all levels (e.g. managing authorities and intermediary bodies), as well as those implementing EU funded projects, related to independent living activities, including civil society, service providers, the academic community, as well as persons with disabilities themselves and their families.

The approach to promoting the right to independent living in this notice takes account of the diversity of disability and of the evolving needs of persons with disabilities throughout their lives through an intersectional approach¹⁰. The notice builds on and complements other initiatives, such as the Council Recommendation on access to affordable high-quality long-term care¹¹, the Council Recommendation establishing the European Child Guarantee¹², the EU Strategy on the rights of the child¹³ and the related Commission Recommendation on integrated child protection systems¹⁴, the Council Recommendation on a comprehensive approach to mental health¹⁶. It also builds on the legislation and guidance provided to ensure accessibility of the built and digital environment, such as the European Accessibility Act¹⁷, the Commission Communication Wave for Europe^{*18}, the Energy Performance of Buildings Directive 2024¹⁹, the Commission Recommendation on building renovation²⁰ and the "New European Bauhaus" initiative²¹, including New European Bauhaus Investment Guidelines²², and transport, as highlighted in the Commission Communication on the Sustainable and Smart Mobility Strategy²³.

2. GIVING EFFECT TO THE RIGHT TO INDEPENDENT LIVING: POLICY ORIENTATIONS FOR THE USE OF EU FUNDS

Independent living provides persons with disabilities with all necessary means to enable them to exercise choice and control over all decisions concerning their lives,²⁴ while being included in and able to interact with the community. This requires their place of residence to not be

¹⁰ In accordance with other Union of Equality Strategies that also pay due attention to intersectionality: Gender Equality Strategy 2020-2025, EU Anti-Racism Action Plan 2020-2025, Roma Strategic Framework for equality, inclusion and participation 2020-2030, and the LGBTIQ Equality Strategy 2020-2025

¹¹ Council Recommendation (2022/C 476/01): <u>Access to affordable high-quality long-term care</u>.

¹² Council Recommendation (EU 2021/1004): <u>European Child Guarantee</u>.

¹³ Commission Communication (COM(2021) 142 final) EU strategy on the rights of the child

¹⁴ Commission Recommendation (SWD(2024) 98 final): <u>Recommendation on developing and</u> strengthening integrated child protection systems in the best interests of the child | European Commission (europa.eu).

¹⁵ Council Recommendation (EU 2022/0263): <u>Early childhood education and care – the Barcelona targets</u> <u>for 2030</u>.

¹⁶ Commission Communication (COM (2023) 298 final): <u>Comprehensive approach to mental health</u>.

 ¹⁷ Directive (EU) 2019/882 of the European Parliament and of the Council of 17 April 2019 on the accessibility requirements for products and services: <u>Directive - 2019/882 - EN - EUR-Lex (europa.eu)</u>
 ¹⁸ Commission Communication (COM(2020) 662 finally A Peneuttion Ways for Europe - graning our provided of the Europe - graning - grani

¹⁸ Commission Communication (COM(2020) 662 final): <u>A Renovation Wave for Europe - greening our</u> buildings, creating jobs, improving lives

¹⁹ Directive (EU) 2024/1275 of the European Parliament and of the Council of 24 April 2024 on the energy performance of buildings (recast)

²⁰ Commission Recommendation (EU) 2019/786 of 8 May 2019 on <u>building renovation</u>

²¹ <u>New European Bauhaus: beautiful, sustainable, together. - European Union (europa.eu)</u>

²² Commission SWD New European Bauhaus Investment Guidelines of 29 July 2024 (europa.eu)

²³ Commission Communication (COM(2020) 789 final): <u>Sustainable and Smart Mobility Strategy</u> – <u>putting European transport on track for the future</u>

²⁴ United Nations Committee on the Rights of Persons with Disabilities: <u>General comment No. 5 on living</u> <u>independently and being included in the community</u>, 2017.

segregated or isolated from the local community. Independent living does not mean living and doing everything alone and getting by without any support, but rather that persons with disabilities are supported towards autonomy and participation, and they are empowered to make the same choices and have the same control over their day-to-day lives as everyone else in society.

Places of residence of persons with disabilities can take many forms, from individual dwellings to cohabitation arrangements, and different types of tenancies (e.g. ownership or rental). The place of residence enables independent living when located in the community and when there is access to in-home and community-based services and support, as well as to services available to the general population (e.g. accessible transport and infrastructure, inclusive education, employment, accessible digital services). Community-based services can be provided at the place of residence of the user, or in the community, with the user commuting to the service. Community-based services include the so-called "residential" services, such as social housing, self-managed co-housing or free matching services. These services aim at ensuring equality and non-discrimination in the exercise by persons with disabilities of their right to adequate housing²⁵.

Places of residence and community-based services share common characteristics that enable independent living, such as: 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 full participation in the community; enable self-determination over day-to-day decisions and activities. They allow for different routines and activities according to preferences of individuals and enable persons with disabilities to live or connect easily with their families and friends and in their local communities.

Giving effect to independent living therefore involves redirecting investments and resources from institutional settings and services to accessible and non-segregated places of residence, community-based services and support²⁶ for persons with disabilities. It requires a paradigm shift from the medical model of care for persons with disabilities to human rights approaches that apply a social model for inclusion and participation and put the person at the centre. It also requires establishing individual plans for persons with disabilities that assess the specific needs of the person and take into account the resources available to the individual (regarding family, income, available services in the municipality, etc.), to match the needs between human and financial resources available.

The transition towards independent living involves phasing out existing institutional infrastructure and services in a **clearly defined timeframe**. This timeframe supports coordination and planning across the relevant departments and levels of government. Timeframes for phasing out institutions are generally most effective when realistic, achievable, communicated to all stakeholders in accessible formats and enabled by the allocation of

²⁵ United Nations Committee on the Rights of Persons with Disabilities: <u>Guidelines on deinstitutionalization, including in emergencies</u>, 2022
²⁶ Support to persons with disabilities "can be provided in various forms, including but not limited to human

Support to persons with disabilities "can be provided in various forms, including but not limited to human support. This can encompass informal support, such as unpaid care and support work, primarily from families and personal networks of persons with disabilities; formal support, provided through support services and support workers (for example, professional personal assistants, sign language interpreters and domestic care workers); or through products (for example, assistive products and new technologies)". United Nations Office of the High Commissioner for Human Rights (OHCHR): Good practices of support systems enabling community inclusion of persons with disabilities, 2023.

sufficient financial resources. It is important to also plan for the future use or repurposing of the institutional facilities once vacated, to avoid incurring additional and unnecessary costs.

Due to the diverse nature of interventions to achieve deinstitutionalisation²⁷ and independent living, those interventions are generally more efficient if underpinned by a **strategic framework** (in the form of a dedicated (part of a) strategy and/or operational action plan at relevant levels), prepared in consultation with persons with disabilities, with:

- a) a clearly defined timeline for the overall deinstitutionalisation process;
- b) needs-based analysis of investment gaps based on the outcome of individual needs assessments and a mapping of existing infrastructure, services and workforce;
- c) time-bound targets and respective indicators;
- d) a dedicated budget and resources, including for the elaboration and implementation of individual plans for the transition to, and for achieving, independent living;
- e) clear governance and division of the responsibilities of the main stakeholders implementing the actions;
- f) a robust and independent quality control system, including accessible complaint mechanisms available to persons with disabilities, their families or persons representing their interests;
- g) monitoring tools to guide the structural reforms needed and related investments.

Ideally, a mapping of existing infrastructure, services and workforce against estimated support needs would be the basis for both the strategies drawn up and the investments for the deinstitutionalisation process. The programming and monitoring of EU funds is to be underpinned by a robust gap analysis at local and regional level and realistic plans to address the gaps.

Investments supported by EU funds provide the opportunity to follow an integrated approach combining service provision with infrastructure and equipment to support independent living. Investments tend to be most effective when high-quality community-, home- and family-based services, that are affordable, accessible and inclusive, are developed first, or, at least, in parallel with corresponding accessible, non-segregated and inclusive infrastructure developments. Investments may also address increasing the provision of accessible, inclusive and non-segregated social housing (for individuals and/or families), including for older persons with disabilities²⁸. These interventions usually require a strong coordination between the various available funding sources, at both the programming and implementation levels.

The process of deinstitutionalisation is guided by the individual plans that provide the assessment of individual needs and accompany persons with disabilities through the transition to independent living, ensuring the continuity of supports. The transition from institutional to community-based services may, in some cases, require temporary interventions with investments in social and healthcare infrastructure aimed at '*the most urgent measures*

²⁷ The 2022 guidelines of the CRPD Committee define deinstitutionalisation as a transition that comprises interconnected processes that should focus on restoring autonomy, choice and control to persons with disabilities as to how, where and with whom they decide to live.

²⁸ See Recital 6 of Regulation (EU)2021/1060: "The Funds should not support actions that contribute to any form of segregation or exclusion, and, when financing infrastructure, should ensure accessibility for persons with disabilities."

*necessary to safeguard residents' physical safety*²⁹, while ensuring the respect of the highest standards of human rights and fundamental freedoms, rooted in the UNCRPD and other relevant human rights frameworks. In addition, intermediate steps, which also respect the highest standards of human rights and fundamental freedoms may be needed: (i) to redress the effects of long-term institutionalisation of persons with disabilities leaving institutions; (ii) and/or to accompany persons with disabilities, including young adults with disabilities, in developing autonomy and self-sufficiency.

The protection of persons with disabilities in situations of natural disasters or humanitarian emergencies also requires special attention, so that emergency efforts do not support the continued institutionalisation and that the process of deinstitutionalisation is reinforced during the recovery measures³⁰.

3. FROM PRINCIPLES TO PRACTICE: PUTTING INDEPENDENT LIVING INTO ACTION

This section describes the main building blocks for independent living and deinstitutionalisation processes to be considered when making investments with the support of EU funds. Non-exhaustive examples of the support that can be provided by EU funding instruments for each area of investments are presented in Section 4. In addition, a list of questions in the Annex gives general guidance on what specific issues could be considered as self-assessment when following the approaches reflected in this Notice.

3.1. Rethinking living arrangements: preventing institutionalisation, moving out of institutions and away from institutional culture.

Ensuring independent living for persons with disabilities also requires efforts to prevent their institutionalisation in the first place. In this context, it is important to consider the diversity of disabilities as well as intersectionality of discrimination that individuals may face:

- In line with the UN Convention on the Rights of the Child³¹ and the Commission Recommendation on integrated child protection systems³², the right of all **children including children with disabilities** to live in a family and in the community, in their best interest, should be protected and supported through investments in preventative measures and early intervention. Such measures include guidance and support for families, including foster families, accessible and inclusive early childhood education and care, accessible and inclusive mainstream education, healthcare and psychosocial support, accessible housing, work-life balance arrangements for family carers, or inhome support for families, including foster families, including foster families, including personal assistance for children, as well as inclusion of children with disabilities in leisure activities. Preventive measures may also be put in place during the transition to adulthood to avoid institutionalisation later in life.

²⁹ Ombudsman Decision on the own initiative inquiry into 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 (OI/2/2021/MHZ)

³⁰ United Nations Committee on the Rights of Persons with Disabilities: <u>Guidelines on</u> <u>deinstitutionalization, including in emergencies</u>, 2022

³¹ United Nations Convention on the Rights of the Child (<u>ohchr.org</u>)

³² Commission Recommendation (SWD(2024) 98 final): <u>Recommendation on developing and</u> <u>strengthening integrated child protection systems in the best interests of the child | European Commission</u> (europa.eu).

- For older persons with disabilities, preventive investments aim to prevent and manage illnesses and the related loss of functions that may develop at an older age, to prevent deterioration in the physical and/or mental health and to strengthen capacity, or ensure the continued support for them to live independently, while also alleviating their experience of loneliness or social isolation, ensuring support and care in the community, as well as to prevent discrimination in accessing services based on old age and/or associated disability status. Persons with neurodegenerative diseases who may require dedicated care, going so far as 24-hour care in a community- or home-based set-up, require special attention. In addition to ensuring that professional support and care are available, adequate support for family and informal carers, including social protection, information and training and, for those who are in employment, family leaves and flexible working arrangements, can contribute to supporting independent living. Investments can enable the person to remain in their home as they age, to improve the accessibility of their dwelling in line with their changing needs, and to retain mobility in their community through accessible public transport and built environment.
- Women and girls with disabilities are subject to multiple types of discrimination and at greater risk of violence both in and outside institutions. It is recalled that Member States must fulfil their obligations under EU law as well as the Council of Europe Convention on preventing and combating violence against women and domestic violence (CETS No. 210) and the UNCRPD aimed at combating gender-based violence. Alongside investments in the development of accessible and affordable community- and family-based services for all persons with disabilities, Member States are encouraged to take appropriate measures to tackle unequal access and barriers faced by women in accessing social services and support³³ and to include a gender perspective in policies to support deinstitutionalisation. In the context of preparing and implementing EU funded projects, it should be borne in mind that persons with disabilities may also be victims of intersectional discrimination and face unequal access in accessing community support services.
- Adults with mental health problems and/or psychosocial disabilities and adults with intellectual disabilities or complex support needs often face barriers in exercising their right to choose and to take decisions over their lives, in particular in systems of guardianship or other limitations to legal capacity. Addressing these challenges require the availability of supported decision-making services (that is, services that provide persons with disabilities the opportunity to develop and express their wishes and preferences in decisions that concern them³⁴) and networks and high-quality, accessible and affordable care and services in the community, including mobile

³³ United Nations Committee on the Rights of Persons with Disabilities, General comment No.5 on Article 19 – the right to live independently and be included in the community, 27 October 2017, CRPD/C/GC/5. General comment No.5 on Article 19 - the right to live independently and be included in the community OHCHR.

³⁴ United Nations Committee on the Rights of Persons with Disabilities, General comment No.5 on Article 19 – the right to live independently and be included in the community, 27 October 2017, CRPD/C/GC/5. General comment No.5 on Article 19 - the right to live independently and be included in the community. OHCHR.

mental health units. Special attention should also be paid to children with mental health problems.³⁵

- **Persons with disabilities living in rural or remote areas** might have far fewer options for services that cater for their needs and preferences. They might be forced to settle for a service that does not suit them, or even to be institutionalised, as a result. They might also be required to relocate far away from family and loved ones to access the services they need. This calls for increasing the availability and diversity of person-centred services in rural areas that enable independent living and inclusion in the community.
- The **risk of homelessness** and poverty is very high for **persons leaving institutions**. This calls for a robust social protection package and support tailored according to the individual plans that include the specific case management for persons with disabilities leaving institutions, to cover immediate and mid-term needs for resettlement.

Affordable assistive technology and innovative accessible technological solutions are pivotal to support autonomous living, to provide at-home and distance care, and to facilitate the transition to independent living for persons with disabilities, including in rural and remote areas. Artificial intelligence (AI) brings an unprecedented potential for new generations of assistive technologies with increased functionality to compensate for impairments and alleviate activity limitations and participation restrictions, including for persons with intellectual and mental disabilities. AI also facilitates the incorporation of accessibility features into mainstream technologies. The interoperability between assistive and mainstream accessible technologies is key, whilst also ensuring ethical and safe usage of such technologies. Training for persons with disabilities and, where relevant, their personal assistants, can help them learn how to use and maintain assistive technologies.

Independent living and deinstitutionalisation imply **access to adequate, affordable, non-segregated and accessible housing** (for individuals and/or families), which takes into account the individual needs and aspirations of persons with disabilities. Investments in adaptable and accessible social housing in the community are key in this domain. The right to independent living is not consistent with the practice of replacing large-scale institutional settings by (or transforming them into) smaller ones where the preconditions for independent living and inclusion in the community are not met³⁶, nor with having persons with disabilities living in their homes without the support mechanisms that enable their inclusion in community. Individual plans and case management approaches aim at identifying the individual support needs of persons with disabilities and ensuring the organisation and delivery of services centred on the user's needs, as well as the continuity of support.

3.2. Person-centred approaches for independent living

In adjusting the landscape of available services and support for persons with disabilities, person-centred approaches for independent living are a priority. Person-centred approaches place the individual at the centre of the services, safeguarding persons with disabilities' choice and control over who is supporting them and ensuring better access to tailored support and a higher degree of coordination of service provision.

³⁵ The European Commission has launched a comprehensive approach to mental health that puts a strong focus on prevention and the social inclusion of persons with mental health problems. See Commission Communication (COM(2023) 298 final) on <u>a comprehensive approach to mental health.</u>

³⁶ See Section 2.

Central to the provision of person-centred care, services and support is the availability and affordability of high-quality community-based services, including personal assistance and professional home care at the place of residence:

- **Personal assistance** is a fundamental enabler of independent living and inclusion for persons with disabilities. It is a service which provides individual help and support to persons with disabilities in all aspects of their lives (e.g. where they live, at work, their social or leisure activities). Ensuring the availability and effectiveness of personal assistance models is essential to support independent living and inclusion in the community. **Personal assistance** can provide persons with disabilities with full self-determination, with access to supported decision-making where necessary. Personal assistance ought to be individualised and needs-based³⁷.
- **Professional home care** and support can, in addition to personal assistance schemes, enable persons with disabilities to continue living in their usual place of residence. Home care can cover a wide range of health and social services, including both medical and non-medical in-home support. Non-medical support may include assistance in daily living activities including cooking, cleaning or other basic activities, like household chores. In parallel, support for family carers is also an important aspect of providing home care.
- In addition to enhancing access to high quality support and care services, persons with disabilities may be supported through the provision of **training and empowerment** to achieve a maximum level of independence and self-sufficiency³⁸.
- The uptake of available services is encouraged by ensuring that **information on services and programmes reaches their intended users.** One of the ways that Member States can do this is **through effective outreach** that targets the user, including in their home, or through relevant disability organisations representing them.

Person-centred funding models, often referred to as individual budgets or personal budgets, can facilitate the tailoring of funding to the individual needs of persons with disabilities. They can enable persons with disabilities and their families to arrange their own support, including personal assistance, preventing their institutionalisation and providing them with choice and control over which services they use, how and where.

3.3. Breaking barriers for inclusion in the community

Preventing isolation and promoting inclusion in the community is only possible if services for the general population are also available, accessible, inclusive and adaptable for persons with disabilities. Investments can thus support equal access to social and health care services, early childhood education and care, education and training, employment, culture and leisure activities. In this regard, accessibility of the built environment, community facilities, infrastructure, goods and services, including transport and housing and of information and

³⁷ UN Committee on the Rights of Persons with Disabilities, Guidelines on deinstitutionalization, including in emergencies, 9 September 2022, CRPD/C/5. <u>CRPD/C/5: Guidelines on deinstitutionalization,</u> including in emergencies (2022) | OHCHR.

³⁸ European Union Agency for Fundamental Rights, 2018, <u>From institutions to community living for</u> persons with disabilities: perspectives from the ground (europa.eu).

communication technologies is essential³⁹. This allows persons with disabilities to easily navigate and move through their communities without facing barriers.

Establishing organised support systems and networks, such as peer support groups or counselling or centres for independent living may also make it easier for persons with disabilities to be included in society and maintain ties with the community. Peer support should be self-directed, independent of institutions and medical professionals, and autonomously organised by persons with disabilities⁴⁰. The benefits of informal networks include empowerment and addressing trauma, participation in the social and political activities of the community and avoiding loneliness. It is beneficial that such activities are also financially supported by relevant authorities.

The creation or development of **labour market opportunities for persons with disabilities** is essential for independent living in order to secure one's own income and to become financially independent. The development of open labour market possibilities requires investing in, among others, work trainers, reasonable accommodation and workspace arrangements and training for co-workers, as highlighted in the Disability Employment Package⁴¹. Social protection systems should be designed to promote a transition to the labour market, avoiding situations where individuals lose income support when getting a job.

Raising awareness of the rights of persons with disabilities, both in the general public and among professionals working with persons with disabilities, is fundamental for changing mindsets and tackling stigma or prejudice surrounding persons with disabilities. Awareness-raising may help to break the culture of institutionalisation and facilitate the move towards independent living and inclusion in the community. In this regard, public awareness campaigns can be developed at national, regional and local levels and include activities targeting the general public, service providers, public officials as well as persons with disabilities and their families.

3.4. Driving and enabling the transformation in service provision

Services addressing specific barriers linked to disabilities respond to the needs of persons with disabilities along the lines of a person-centred approach. High quality services comply with **quality** requirements, which take into account the lived experience of persons with disabilities and guarantee that principles, such as self-determination, free choice and independent living are upheld and promoted. Such quality principles are important in the design and implementation of quality assurance and accountability mechanisms for a wide range of community support services, as well as mainstream services. Quality assurance frameworks and accountability mechanism across the EU can therefore evolve to contribute to improving the persons' lived experience.

Building up a skilled and sufficient workforce and improving the attractiveness of the care and support services sector, including by ensuring fair working conditions, is important for ensuring quality of services. The recruitment and retention of qualified

³⁹ During the 2021-2027 period, accessibility for persons with disabilities must be taken into account throughout the preparation and implementation of programmes supported by the ESF+ and the ERDF. Article 9(3) of Regulation (EU) 2021/1060.

⁴⁰ UN Committee on the Rights of Persons with Disabilities, Guidelines on deinstitutionalization, including in emergencies, 9 September 2022, CRPD/C/5. <u>OHCHR.</u>

⁴¹ A flagship initiative of the Strategy for the Rights of Persons with Disabilities <u>https://ec.europa.eu/social/main.jsp?catId=1597&langId=en</u>

professionals is a growing challenge in the sector, which is characterised by difficult working conditions, low pay, part-time and undeclared work together with insufficient investment in training and professional development⁴². Measures to support independent living and inclusion in the community will require a qualified, skilled, and sufficiently large workforce. In addition, it is important to develop and strengthen the profession of personal assistant, including through the provision of necessary training, access to social protection and perspectives for career progression. This requires clear legal frameworks and public budget allocations for providing personal assistance.

Effective policies promote training and support inclusive education to provide disability awareness and encourage sensitivity among staff in the sector, including on invisible disabilities such as autism. Upskilling and reskilling opportunities can improve both the sector's attractiveness to potential employees and drive care and support services towards excellence. Training focussing on human rights awareness and person-centred approaches in service delivery, as well as on disability-specific content relevant to communication, mobility, use of assistive technologies, etc. can be provided, where possible by persons with disabilities themselves. In this context, a range of programmes 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 sector⁴³; and (ii) a toolkit on the use of European Social Fund+ funds to train staff involved in independent living⁴⁴.

3.5. Consultation and participation

Pursuant to Article 4(3) of the UNCRPD, Parties must closely consult and actively involve persons with disabilities, including children with disabilities, through their representative organisations in the development and implementation of legislation and policies to implement the UNCRPD and in other decision-making processes concerning issues relating to persons with disabilities. Consultations are an opportunity to meaningfully involve persons with disabilities, in all their diversity, including those with lived experience of institutions and their families, as well as children⁴⁵ and their legal representatives. It is important to involve persons with complex support needs, as they are more at risk of being institutionalised, and left behind in the transition towards community-based services⁴⁶. The views and preferences of persons with disabilities should be considered throughout the design, implementation and evaluation of services and plans aimed at them, including measures to support independent living and inclusion in the community. Where relevant, such participatory processes should be carried out at all levels of government, including national, regional and local levels.

⁴² This is also an objective of the Council Recommendation on long-term care where Member States are encouraged to invest in the long-term care workforce, improving their working conditions and access to training. Council Recommendation (2022/C 476/01): <u>Access to affordable high-quality long-term care</u>.

 ⁴³ Pact for Skills, Driving up training and lifelong learning in long-term care – A Skills Partnership, 2 May 2023. Skills Agreement Layout (europa.eu).

⁴⁴ Community of Practice on Social Inclusion, <u>Toolkit: Using the European Social Fund Plus (ESF+) for</u> <u>Staff Training in Independent Living Support</u>.

⁴⁵ In line with the right of the child to participation, as enshrined in Article 12 of the UN Convention on the Rights of the Child, Article 24 of the Charter of Fundamental Rights of the EU

⁴⁶ UN Committee on the Rights of Persons with Disabilities, General comment No.5 on Article 19 – the right to live independently and be included in the community, 27 October 2017, CRPD/C/GC/5. <u>General comment No.5 on Article 19 - the right to live independently and be included in the community | OHCHR</u>.

Effective consultations on decision-making processes to support the deinstitutionalisation process and the transition to community life imply that information is provided in accessible formats supported by appropriate outreach. Various accessibility requirements have been set at EU level, notably on services and products or the digital and physical environment in the European Accessibility Act⁴⁷ and for all public sector websites and mobile applications in the Web Accessibility Directive⁴⁸. Member States and service providers are further encouraged to provide information in accessible formats for persons with different types of disabilities, including use of sign language, braille or easy-to-read formats, and that are age appropriate.

Partnership in the implementation of EU funding, with all relevant stakeholders, such as relevant bodies representing local and regional authorities, social services, civil society and independent fundamental rights bodies and human rights organisations, remains a key principle in the design and implementation of the programmes supported by EU funds.

4. SUPPORT FROM THE EU FUNDS TO THE TRANSITION TO INDEPENDENT LIVING AND INCLUSION IN THE COMMUNITY OF PERSONS WITH DISABILITIES

For many years, EU funds have supported national and regional investments and structural reforms to develop family- and community-based services instead of institutional care. The funds help in this way to improve the situation on the ground.

Member States have been encouraged to complement their national funding with the funds under the Common Provisions Regulation (CPR), notably the European Social Fund Plus (ESF+) and the European Regional Development Fund (ERDF), to offer a differentiated landscape of quality, accessible, non-segregated, person-centred, affordable, non-residential community-, home- and family-based services.

Member States also included reforms and investments promoting independent living and equal opportunities for people with disabilities in their national recovery and resilience plans (RRPs) under the Recovery and Resilience Facility (RRF). The Technical Support Instrument (TSI) has supported reforms related to the socio-economic inclusion of persons with disabilities.

The InvestEU programme has supported investments in accessible and affordable social housing to improve accessibility and access to housing for persons with disabilities⁴⁹.

In the context of enlargement policy and the European neighbourhood policy, the Instrument for Pre-accession Assistance⁵⁰ and the Neighbourhood, Development, and International Cooperation Instrument⁵¹ support investments in the area of independent living and

⁴⁷ Directive 2019/882/EU, European Accessibility Act, Section III of Annex I, 17 April 2019. <u>European Accessibility Act</u>. Member States were obliged to turn the act into their national laws by 28 June 2022, and apply its rules from 28 June 2025. From the latter date, consumers will be able to file complaints before national courts or authorities if services do not respect the new rules.

⁴⁸ Directive (EU) 2016/2102 on the accessibility of the websites and mobile applications of public sector bodies

⁴⁹ Examples of projects in the area of affordable and social housing supported by InvestEU can be found here: <u>InvestEU operations - list - European Union (europa.eu)</u>.

⁵⁰ Regulation (EU) 2021/1529 of the European Parliament and of the Council of 15 September 2021 establishing the Instrument for Pre-Accession assistance (IPA III).

⁵¹ Regulation (EU) 2021/947 of the European Parliament and of the Council of 9 June 2021 establishing the Neighbourhood, Development and International Cooperation Instrument – Global Europe, amending

deinstitutionalisation. For Ukraine specifically, the Ukraine Facility⁵² provides for support to the deinstitutionalisation of care and rehabilitation of persons with disabilities.

The implementation of EU funds requires respect for fundamental rights and compliance with the Charter.⁵³ **The horizontal enabling condition** on the implementation and application of the UNCRPD in cohesion policy funding requires Member States to have in place **a national framework to ensure the implementation of the UNCRPD.** This national framework must include objectives with measurable goals, and specific arrangements to ensure that an accessibility policy, legislation and standards are properly reflected in the preparation and implementation of programmes.

The UNCRPD enabling condition is one of the prerequisites for effective implementation of the funds that needs to remain respected throughout the programming period. The provision on horizontal principles, in particular on ensuring **accessibility** for persons with disabilities must be taken into account throughout the preparation and implementation of programmes⁵⁴.

Furthermore, the horizontal enabling condition also requires reporting to the Monitoring Committee on cases of non-compliance with the UNCRPD of operations supported by the Funds and complaints regarding the UNCRPD.

In addition, for the purpose of making use of the ERDF and the ESF+ for social inclusion investments, the thematic enabling condition 4.4 under the CPR requires the Member States to have in place national or regional strategic policy or legislative frameworks for social inclusion and poverty reduction, including measures to prevent and combat segregation in all fields, and measures for the shift from institutional to family- and community-based care.

For investments under healthcare and long-term care, thematic enabling condition 4.6 under the CPR requires a national or regional strategic policy framework to be in place, containing a mapping of health and long-term care needs, as well as measures to promote community and family-based services through deinstitutionalisation, including prevention and primary care, home care, and community-based services. Member States have been required to ensure that investments supported with Cohesion funds are in line with the relevant policy and legal provisions and frameworks required under the enabling conditions, which need to be respected throughout the whole programming period⁵⁵.

EU funding has helped support some key areas of investment and reforms to promote the right of independent living and advance the process of deinstitutionalisation. These include:

• non-segregated housing options in the mainstream community, in particular accessible social housing and services that facilitate access to housing;

and repealing Decision No 466/2014/EU of the European Parliament and of the Council and repealing Regulation (EU) 2017/1601 of the European Parliament and of the Council and Council Regulation (EC, Euratom) No 480/2009.

⁵² Regulation (EU) 2024/792 of the European Parliament and of the Council of 29 February 2024 establishing the Ukraine Facility.

⁵³ Article 9(1) 2021-2027 Common Provisions Regulation on horizontal principles. See also Commission Notice Guidance on ensuring the respect for the Charter of Fundamental Rights of the European Union when implementing the European Structural and Investment Funds ('ESI Funds') (2016/C 269/01)

⁵⁴ Article 9(3) of Regulation (EU) 2021/1060.

⁵⁵ Article 15 of Regulation (EU) 2021/1060

- person-centred non-residential community-, family- and home-based services, including support for personal assistants and social workers, home care and networks of peer support; related equipment and assistive technologies; capacity building of workforce and public administration;
- ensuring accessibility and inclusiveness of complementary quality mainstream services, such as early childhood education and care, education, employment, healthcare;
- technical support for the design and efficient implementation of reforms, referred to above.

This section provides more detailed examples of the types of measures fostering the development of community and family-based services and support for independent living and the implementation of deinstitutionalisation strategies that EU funds (e.g. ESF+, ERDF, RRF, TSI or InvestEU) can help support. The examples provided can support the programming and implementation of EU funded programmes in line with the UNCRPD.

4.1. Comprehensive national strategies and action plans to support independent living and deinstitutionalisation

Examples of Member States' actions that could be supported by EU funding (non-exhaustive list)⁵⁶:

- assessments, analysis, in-depth reviews, mapping of infrastructure, services, human capital, skills, complaints mechanisms, as the basis for the preparation of the strategic frameworks, especially in cooperation with academia, civil society organisations, regional and local authorities, social services, independent human rights bodies and human rights organisations;
- consultative process on the preparation of the strategic framework (including roundtables, conferences, workshops, on-the spot visits and other relevant activities);
- developing data collection systems on persons in institutions and at home in need of care and an overview of persons wanting to leave residential institutions;
- capacity building for the preparation of a strategic framework on the transition to independent living, and for the set-up of a coordination platform to foster an integrated approach of social and health systems in the Member State, as well as synergies with labour market, education, law enforcement;
- implementation and monitoring of the strategic framework, also including communication and evaluation;
- technical support for the design and efficient implementation of actions referred to above, including support with testing, piloting of actions, building up quality assurance and control capacity for authorities.

⁵⁶ Examples also relevant for EU external action and EU-funded projects internationally within their scope of support.

4.2. Rethinking living arrangements: preventing institutionalisation, moving out of institutions and away from institutional culture

EU funds help to support investments by Member States in accessible and inclusive individual social housing. The Commission has recently published a toolkit providing an overview of all the opportunities for support offered by EU funds in the field of social housing and associated services ⁵⁷.

Examples of actions where EU funding can support Member States (non-exhaustive list):

- the provision of individual accessible social housing, such as individual apartments in the mainstream community, corresponding equipment supporting independent living, and support by personal assistants;
- support at home through investments in adaptation and accessibility (including the introduction of e-health services), as well as in equipment and assistive solutions;
- improving access to adequate non-segregated housing and essential services for persons with disabilities, accompanying measures to improve access to accessible housing, in particular social housing;
- measures to prevent institutionalisation tailored to the needs of different target groups (e.g. early intervention, guidance and support to families, accessible and inclusive early childhood education and care for children with disabilities, access to employment, community-based services in health and social care, assistive solutions, support systems);
- measures to help support inclusion during crises and rapid response efforts, as well as inclusion in evacuation, relief and recovery measures and full accessibility of support in situations of disaster and humanitarian emergency.

4.3. Person-centred approaches for independent living

Examples of actions that could be supported with EU funding (non-exhaustive list):

- development of an integrated and comprehensive network of person-centred community-based services, including for persons with intellectual and/or psychosocial disabilities, such as personal assistance, home care, crisis support, counselling services;
- community-based infrastructure that provides services to promote independent living⁵⁸;

⁵⁷ European Commission, Social housing and beyond - Operational toolkit on the use of EU funds for investments in social housing and associated services, 18 April 2024. <u>Publications catalogue -</u> <u>Employment, Social Affairs & Inclusion - European Commission (europa.eu).</u>

⁵⁸ This may also include adapting and making accessible mainstream services, such as general practitioners offices, physiotherapists, psychologists, occupational therapist, other specialists. Needs of persons with disabilities should not be addressed in parallel services for just one target group but through facilitating their access to the already mainstream services (and extending their capacities and services they offer).

- measures addressing the specific needs of carers of persons with disabilities, especially family members;
- measures related to accessible infrastructure, products and services as well as assistive technologies and services;
- measures to introduce/develop personal budgets and their piloting; innovative measures for the provision of support services in the community;
- support for employment and active labour market policies, as well as accessibility and reasonable accommodation, aimed at improving the employment of persons with disabilities;
- support to employers and employees on combating stereotypes and creating positive working environment for persons with disabilities, paying attention to different disabilities, including intellectual disabilities;
- technical support for the design and efficient implementation of actions referred to above, including support with testing, piloting of actions, capacity building for authorities.

4.4. Breaking barriers for inclusion in the community

Examples of actions that could be supported with EU funding (non-exhaustive list):

- measures to improve access to and the accessibility and inclusiveness of mainstream social services, in particular employment and education-related services, community-based social assistance, healthcare and psychological services;
- support to increase access to and completion of all levels of education and training (including for adults) for persons with disabilities;
- support for the enrolment of children with disabilities in inclusive mainstream early childhood education and care services alongside children without disabilities, including via innovative approaches and securing sufficient numbers of qualified staff (teachers/rehabilitators/speech therapists/other specialists);
- increasing access to e-services on an equal basis with others to promote the e-inclusion of persons with disabilities, and investment in digital literacy including skills in digital accessibility;
- development and adaptation of social, health, employment, housing, culture & tourism, education and training infrastructures, that are accessible for persons with disabilities, mobile units (e.g. for (mental) health);
- the development of accessible means of transport to improve access to mainstream services;
- technical support for the design and efficient implementation of actions referred to above, including support with testing, piloting of actions, capacity building for authorities.

4.5. Driving and enabling the transformation in service provision

Examples of actions that EU funds could help support (non-exhaustive list):

- training on independent living for public authorities, healthcare as well as social and support services staff, including personal assistants and social workers, also in the context of the shift from institutional care to family- and community-based services and preventive actions;
- development of curricula for occupational profiles/jobs in community-based support services and mainstream services;
- improvement of the status and professionalisation of social services, including through upskilling and reskilling;
- developing training infrastructure and/or equipment, including to support the development of accessible and assistive technologies and services, targeting the personnel of non-residential family- and community-based services;
- development, piloting and implementation of quality assurance and accountability mechanisms;
- technical support for the design and efficient implementation of actions referred to above, including support with testing, piloting of actions, capacity building for authorities.

4.6. Consultation and participation

Examples of actions that EU Funds could help support (non-exhaustive list):

- involvement of civil society, independent fundamental rights bodies and human rights organisations representing persons with disabilities, in the design, implementation (development of selection criteria, calls for proposals), monitoring, and evaluation of the programmes, including in the monitoring committees;
- involvement of civil society, independent fundamental rights bodies and human rights organisations representing persons with disabilities in the monitoring and evaluation of strategic frameworks.

5. MONITORING PROGRESS

Improving the collection of disaggregated data

It is important to monitor progress towards the deinstitutionalisation of persons with disabilities to both support the implementation of the long-term strategic framework in place and inform policy choices at national, regional and local level. Monitoring requires improved data collection systems in terms of coverage (e.g. on the number and living situation of persons with disabilities living in institutions), disaggregation (by age, gender, disability type), and trend. Eurostat is working with Member States on developing data collection on persons living in institutions, who are currently not captured by EU-wide surveys. Work is ongoing to investigate the possibility to include persons living in institutions in the future data collection waves of the European health interview survey (EHIS), with a periodicity of 6 years. The proposed methodology will be tested in the coming years and could be considered for the next EHIS wave scheduled for 2031 (in case of a positive outcome of the testing).

Monitoring investments

Deinstitutionalisation processes can only be effective when they are underpinned by a strategic long-term framework, with a clear timeframe, time-bound targets, including on the closure of institutions and the number of people making the transition to community-based services, allocated budget, related monitoring tools and performance review process. Persons with disabilities and their representative organisations should be involved and meaningfully consulted at all stages, from the drafting of the strategies to the monitoring and evaluation of investments. The involvement of persons with disabilities as service users and their representative organisations should not be limited to providing feedback, but also include participation in following up on evaluation results, to plan any improvement and adjustments. Independent fundamental rights bodies and human rights organisations are among the stakeholders to be involved in the monitoring of investments. The results of evaluation and monitoring should be made publicly available, in order to ensure accountability and support meaningful public debate on deinstitutionalisation.

In external action, investments for persons with disabilities in general, and in independent living in particular, are monitored through the OECD disability marker, which tracks how disability is mainstreamed in external cooperation and emergency assistance.⁵⁹

⁵⁹

Guidance note: Leaving no one behind - Disability inclusion in EU external action. Available from: https://capacity4dev.europa.eu/media/131345/download/c69c327a-5719-4ae9-984b-8f1793b8604a

ANNEX SELF-assessment tool for operations under EU Funds ensuring the independent living of persons with disabilities. Key questions

The questions below can be used as examples to self-assess the alignment of operations and projects to the approaches described in the Commission Notice Guidance on independent living and inclusion in the community, in light of the provisions of the Charter of Fundamental Rights of the EU and the UNCRPD.

This self-assessment tool is intended purely as a guidance tool and does not create any legal obligations on Member States⁶⁰. It provides only an indicative basis to facilitate possible self-assessment, it is not binding and does not prejudge the compliance of the operations and projects concerned with the applicable requirements.

GENERAL

- Are the rights of persons with disabilities, as indicated by the UNCRPD, affected by the operation/ project?
- Are the rights of persons with disabilities as enshrined in the EU Charter of Fundamental Rights affected by the operation/project?
 - o Dignity
 - o Non-discrimination
 - Privacy and private life
 - Freedom of expression
 - Protection of personal data (is there any transfer of data? If yes, it is recorded? Notified? Secured? Safeguarded?
 - Rights of the child (if referring to children)

Is the operation/project part of a strategic framework on independent living and deinstitutionalisation?

CONCEPTUAL

- Do you use a definition of persons with disabilities aligned with the UNCRPD and EU legally binding instruments (i.e. Directive 2019/882)?
- If the operation/project entails the provision of support services for persons with disabilities, are measures planned to ensure that service providers are trained and knowledgeable on the human rights of persons with disabilities?
- Does the operation/project affect the right of persons with disabilities to independent living and inclusion in the community (for example, moving persons out of their home, placing persons in institution)?
- Does the operation/project fully respect and not restrict the legal capacity of persons with disabilities?
- Does the operation envisage preventive measures to avoid abuse or violence against persons with disabilities? Are there reporting mechanisms and remedial actions envisaged in such cases?
- Have you checked that the initiative does not discriminate against persons with disabilities?

⁶⁰ Or for beneficiary countries in the context of EU external action and EU-funded projects internationally.

- Does the operation/project take account, where appropriate, the specific needs of women and girls with disabilities?
- Does the operation/project take account, where appropriate, the specific needs of older people, homeless, and LGBTIQ people with disabilities?
- Does the operation/project respect the rights of children with disabilities (including those deprived of parental care)?

INDEPENDENT LIVING AND INCLUSION IN THE COMMUNITY

- If the operation/project involves infrastructure:
 - Have you checked that there is no spatial segregation and can this be demonstrated?
 - Are users of the infrastructure easily able to reach and move within the community (transport, shops, entertainment, services....)
 - Does the operation/project respect the choices of individuals benefiting from it?
 - Is accessibility of the infrastructure ensured?
- When the operation/project involves support services for persons with disabilities:
 - Are service recipients informed of their rights and are there independent control mechanisms?
 - Do persons with disabilities have a say on the services they receive and on how and when those services are received?
 - Do persons with disabilities need to share assistants without having a say in the choice?
 - Can persons with disabilities get the support and services at home or in the community?
 - Is it guaranteed that the provision of services and support is not conditional on particular living arrangements?
 - Does the operation/project risk marginalising persons with disabilities? Is there a justification provided that it is not the case?
- On persons benefiting from the initiative:
 - Can they choose their place of residence or decide to remain at home?
 - Can they decide with whom they live and not be forced to share a room or a housing with persons not of their choice?
 - Can they move freely? Express their preferences and choices?
 - Do they have control over their day-to-day life decisions, routines and time schedules?
 - Are they able to select the activities they want to do and for example join education, employment, leisure, services in the community without restrictions imposed by the settings of the initiative?
- Does the operation/project demonstrate how persons with disabilities will remain in/return to the community? Are services provided to the general population disability inclusive and accessible for persons with disabilities?
- Does the operation/project ensure accessibility of all services it addresses?
- Is the provision of assistive technologies considered?

CONSULTATION

- Have you involved and consulted persons with disabilities and their representative organisations in drawing up the operation/project?
- Does the operation/project contain plans for the involvement of persons with disabilities or their representative organisations in its implementation, monitoring and evaluation?