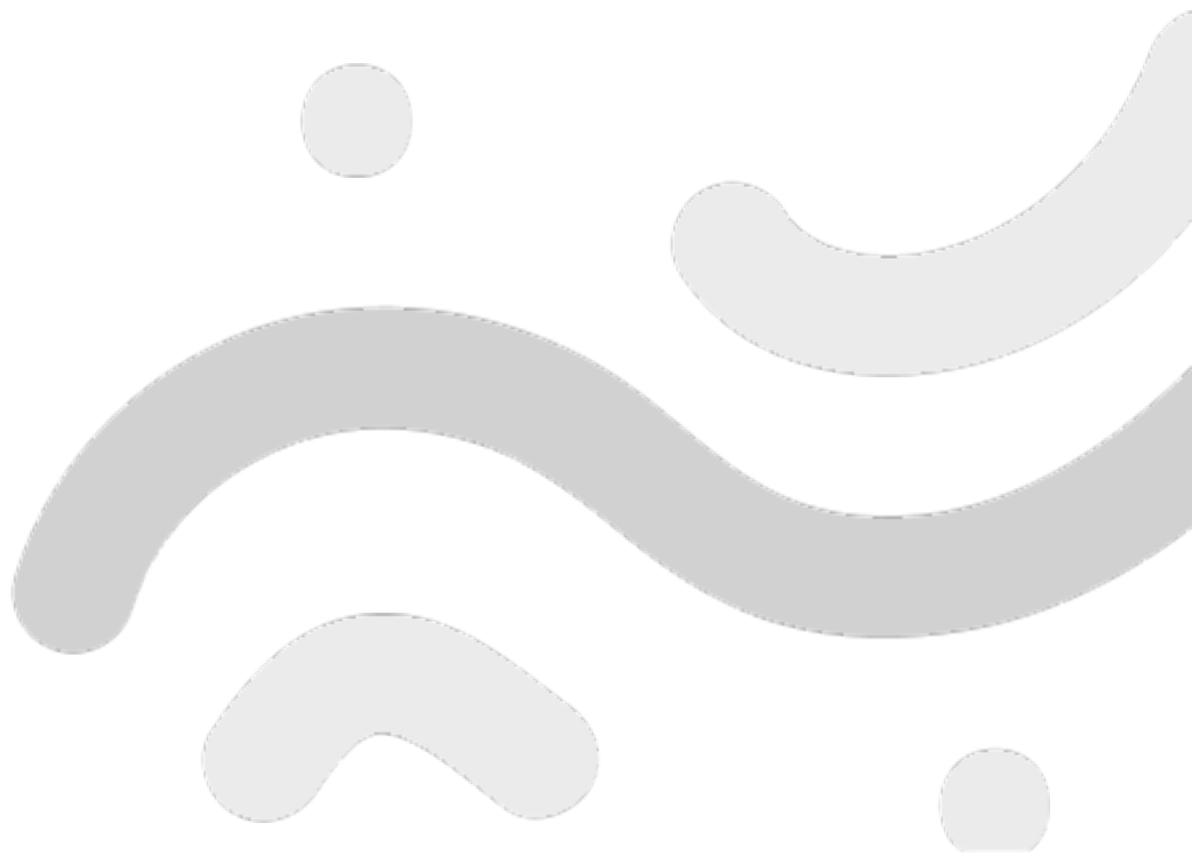


EU Guidance on independent living and inclusion in the community



European Expert Group on the transition from institutional to community-based care

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About the EEG

The European Expert Group on the transition from institutional to community-based care (EEG) is a broad coalition of stakeholders gathering people with care or support needs as well as service providers, public authorities and intergovernmental organisations.

The EEG represents:

- Children and their families;
- People with disabilities and their families;
- Homeless people;
- People experiencing mental health problems;
- Service providers;
- Public authorities;
- UN organisations.

The EEG advocates to replace institutionalisation with family- and community-based support. The EEG reminds the EU and Member States of their obligation to stop funding and to replace institutionalisation with family- and community-based support; based on:

- United Nations Convention on the Rights of Persons with Disabilities, its general comments and its guidelines on deinstitutionalisation;
- United Nations Convention on the Rights of the Child;
- The UN Guidelines on the Use and Conditions of Alternative Care for Children;
- European Fundamental Rights Charter.

The EEG provides expertise on the transition from institutionalisation to family- and community-based support. We focus on how EU funding, law and policy should be used to facilitate the transition, including:

- phasing out expenditures on institutions while transferring them to the development of community-based forms of support
- speeding up the development of community and family based forms of support
- making resources available to expand capacity and quality of family- and community-based support;
- making resources available to facilitate access to housing, early childcare, inclusive education and accessible general public services and built environment;
- making resources available for monitoring of reforms at national level.

Further details on the guidance on EU funding can be found in the EEG EU Funds Checklist to Promote Independent Living and Deinstitutionalisation on the EEG website.

Political Context

The European Union has recently taken measures to facilitate the transition from institutional to community- and family-based services in the Member States. To date, its main tool for doing so have been the rules governing the use of EU funds, particularly funds such as the European Social Fund (ESF+) and the Regional Development Fund (ERDF). The Regulation outlining the rules around the use of such EU funds is known commonly as the Common Provisions Regulation. In the most recent version of this Regulation, entered in force in 2021, it is stated that the EU funds covered by the Common Provisions Regulation need to “be implemented in a way that promotes the transition from institutional to family-based and community-based care”. It also stresses that “The Funds should not support actions that contribute to any form of segregation or exclusion, and, when financing infrastructure, should ensure the accessibility for persons with disabilities.”¹

However, the EU Regulations concerning how funding is used in the Member States can end up being misinterpreted by the National Managing Authorities in the Member States, when deciding on where to allocate the money. Rules within the Common Provisions Regulation therefore do not entirely prevent cases of institutions being built or renovated using EU funds. Furthermore, they do not cover how countries spend their own national budget, meaning that State funding can still go towards institutions instead of family- and community-based services supporting independent living. For these reasons, the advances seen in EU Member States regarding the number of institutionalised people over the past decade have been moderate. In some Member States the EEG has even reported regressions in the transition away from institutional care for certain groups.²

In 2021 the European Commission launched its EU Strategy for the Rights of Persons with Disabilities 2021-2030. The Strategy contains a number of initiatives, among them a series of “flagship initiatives” – the pillars of the Strategy. In order to address continued financing of institutional care, and insufficient steps taken to foster independent living and social inclusion, one of the flagship initiatives as announced for 2023 is “guidance **recommending to Member States improvements on independent living and inclusion in the community**”. This guidance note should provide further instruction on the use of EU funds but would also prove useful to Member States when allocating their national funding.

¹ EUR-Lex - 32021R1060 - EN - EUR-Lex (europa.eu)

² eeg-di-report-2020-1.pdf (wordpress.com)

This position paper by the EEG aims to present to the European Commission, in its preparation of this Guidance, what the EEG recommend to see included under this initiative in order to break the cycle of continued funding in services that do not foster inclusion or independent living. As the main European coalition of organisations working on de-institutionalisation, our ask is that the points outlined below – limited to the areas within the EEG’s mandate - will be conveyed clearly in the Commission’s own guidance to the Member States.

Guidance on Independent Living and Inclusion in the Community

Guidance on this important topic requires a clear understanding of what kind of expenditures to avoid (namely those that trigger segregation) and which ones are to be approved and further supported.

Below the EEG outlines six guiding actions that Member States and local authorities should take to ensure their policies and funding are supporting independent living and inclusion in the community. The following recommendations need to be seen as taking place simultaneously and not as a step-by-step guide. They offer a mixture of red flags to be aware of and avoid, positive practices to put into place, and long-term actions to implement to be able to monitor progress. So let’s begin...

Action 1

How to spot an institution and ensure funding does not go to continuing institutional care

The first step to supporting the independent living and inclusion in the community of persons with disabilities, with mental health issues, homeless people and other people **with support needs, is to ensure that funding for institutional forms of care is halted.** To do this, the authority allocating the funds needs to be able understand and recognize what an institution is.

An institution is a care setting that displays any of the following characteristics:

A. Residents are isolated from the broader community and/or compelled to live together.

B. Residents do not have sufficient control over their lives and over decisions which affect them.

C. The requirements of the organisation itself tend to take precedence over the residents' individual needs.

Further clarification of what constitutes an institution can be found in [General Comment 5 of the United Nations Convention on the Rights of Persons with Disabilities](#) and [the CRPD Guidelines on deinstitutionalisation including emergencies](#).

THE CHARACTERISTICS ABOVE SHOULD BE SEEN AS RED FLAGS, AND ANY EXPENDITURES IN THIS TYPE OF SERVICE SHOULD BE HALTED.

Action 2

How to invest money in services that promote independent living and inclusion in the community

Community-based services that promote independent living and inclusion in the community also present their series of recognisable characteristics. To make sure to invest in support services that foster independent living and the inclusion in the community, while putting at the centre the right for the service user to choose services adapted to their need and wishes, investments in support services should fulfil the following criteria:

A. Giving the service user control over their own life

1. The person must be able to decide where and with whom they live based on personal preferences. Therefore, the type of service a person receives must have been chosen by them, and all the information about the various options presented to them in a way that is clear and understandable. Supported decision making should be available when a person needs it.

2. Each locality should have on offer a sufficient range of different types of services and ensure the accessibility of mainstream services, to respect the right to choose of the service user. Indeed, together with each individual's legal capacity, variety, accessibility, affordability and sufficient availability of the different options is what makes the persons "right to choose" a reality. According to paragraph 8 of the CRPD Guidelines on deinstitutionalisation including in emergencies, released in 2022, "institutionalisation must never be considered a form of protection of persons with disabilities, or a choice".

3. The services on offer should include personal assistance for those in need, without discrimination and ensuring that the level of personal assistance provided meets each person's needs for support. Localities should ensure that there is sufficient provision of personal assistance service to meet the demand and respect the right to choose of the services users. In cases where this will not be the case, local funding must adapt to the needs, direct support by state budget might be required.

4. The budget available for assistance should be delivered to the person who then uses the service, or their families, rather than being paid directly to the service provider. This puts the power of service selection more squarely in the hands of the service user.

5. Peer support can be offered for this purpose, as well as forms of supported decision-making for people requiring support in making choices about their living arrangements and planning for inclusion in the community. Substitute decision-making schemes should not be considered as a viable and adequate form of support.

6. Encourage the use of “inclusive budgets” to allow services to shift towards fully community-based support, with fully flexibility to develop special support packages according to the different needs.

B. The location of the service must not result in the person being more segregated or cut off from their community

Location is one of the elements that can be decisive in evaluating whether services support inclusion and independent living, or whether they further segregate people from their communities. Below are some characteristics regarding location that indicate they are promoting inclusion. Positive locations could include:

- 1. A person living in regular housing**, such as in an apartment block or a house, with support provided to live there if required.
- The provision of housing (contract with a regular landlord or the service provider overseeing the provision of personalised accommodation) **not being tied directly to the support services a person receives**. This will allow the person to move house and change their accommodation as it suits them, without losing their support package in the process.
- 3. Ensuring that the person’s accommodation is not on the same site as the place they** work or study etc. This means that a person will travel to work, school, etc. thus not doing everything in the same place they are living and remaining segregated within that one location. The recent development of smart working represents an exception as this modality as it is often voluntary and might still contribute to community inclusion.
4. When personalised accommodation is provided as part of a larger support service **provision, this should be within the community and located alongside other** accommodation. Housing should not be provided in isolated settings or clustered in localities where the residents are themselves predominantly service users.

5. Any adequate accommodation is organised to contrast the “institutional culture” which may concern any residential settings, regardless of the size.

C. The service must be designed around the requirements of the person

1. Services should be flexible in offering different levels of support, ranging from 24 hours per day, to several hours per week, depending on each individual’s needs and requirements. The needs may vary over time, requiring a continuum of support (from light to intensive forms of support).

2. Services should be right-based, centred around the needs and wishes of the people they support.

3. Services should focus on establishing and maintaining the person’s social roles (employment, family, friends, etc.). Moreover, in the assessment and design of services, there should be specific attention to integrating as well both families and family carers’ needs.

4. To the greatest extent possible, services that the person requires in different areas of their life should be covered by mainstream services. Where mainstream services are not accessible and equipped to meet the needs of everyone, for example for persons with disabilities, the local authorities should start redesigning and funding these services to be used by all as a priority. This includes services such as healthcare, education, transportation etc.

5. The provision of services should be accompanied by a well-trained and adequate workforce. Training of the workforce should be considered as essential to support in the implementation of new support methodologies and worker profiles and ensure that institutionalising practices are not established in the forms of support based in the community. Mainstream services workforce should also be trained on inclusion and rights-centred approaches.

6. In order to ensure the provision of adequate and quality services, it is essential that Member States recognize the current shortage of staff needed to provide satisfactory support.

THESE CHARACTERISTICS ARE LIKELY TO INCREASE THE ABILITY OF PEOPLE TO CHOOSE THE SUPPORT THEY RECEIVE, TO MAKE THE MOST SOUGHT-AFTER KINDS OF SERVICES MORE READILY-AVAILABLE, AND TO IMPROVE AUTONOMY AND INCLUSION IN THE COMMUNITY.

Action 3

How to adapt services for the specific needs of children and minors, and how to offer support to families

Inclusion in the community is very much at the heart of the support children and it should be offered. This applies especially for children with disabilities and from minority backgrounds, such as Roma children or unaccompanied minors who arrive in the EU as refugees. Support services for children should therefore be approached in the following ways:

A. The priority should be on preventative measures stopping children being separated from their families whenever possible. For children with support needs, families should be given access to in-home support, including personal assistance, and financial benefits for living expenses as well as for necessary adjustments of households to enable the child to stay with the family while receiving the tailored support they need. Families should also be given access to good mainstream services beyond financial support and work life balance measures, including counselling, advice, breaks for family carers and baby-sitting services etc.

B. When parents or family members act as informal care-givers, financial support should be provided to ensure that they are compensated for the service they provide, and to off-set loss of income and pension rights from other sources, family care givers should be recognised and supported by accessible, after affordable and inclusive services in the community.

C. When it is impossible for a child to remain with their own family, the next step should be to facilitate entry into a family setting via fostering. In case children are unable to live with their own parents, priority should be given to exploring the resources of the wider family (also known as kinship care). If, assessment, these are not feasible or appropriate then a suitable unrelated foster family should be sought. Linking a child with an appropriate foster family requires taking into account the specific needs of the child and giving them a simple and confidential means of bringing up any concerns they have about their host family once a placement has been found. It is crucial that foster families also be an option for children with higher support needs, and that foster families are supported financially and with technical support in meeting the requirements of children with disabilities or medical conditions. The trainings and other support mechanisms should be developed and made accessible for foster parents taking care of children with special needs.

In paragraph 44 of the CRPD Guidelines on deinstitutionalisation including in emergencies, it specifies that "a healthy living arrangement should allow a child to establish a stable relationship with a committed adult caregiver, and every effort should be made to avoid multiple placements of children who do not live with their family of origin".

Action 4

Promoting independent living and inclusion through accessible environments

Facilitating independent living and social inclusion is not just about funding services. It is also about making spaces more accessible and building societies in a way that no longer prevents people from participating. It is especially important to plan ahead with accessibility in mind, not only for persons with disabilities, but also in light of Europe's ageing populations. The following principles should be mainstreamed into funding for urban planning:

- Prioritise the accessibility of public spaces and all public buildings for persons with reduced mobility and other disabilities
- Increase the stock of accessible mainstream housing by requiring accessibility as a standard for all newly-build properties
- Increase the stock of accessible mainstream housing by identifying housing stock that can be retroactively made accessible to persons with disabilities and making it a funding priority to update them
- Increase the accessibility of educational establishments for all levels of education: this requires ensuring the physical accessibility of buildings, training of teachers and classroom assistants to be able to welcome learners with disabilities into mainstream educational settings, provision of sign-language interpreters and learning material in Braille when needed, and other support for the learner depending on their individual requirements
- Provide incentives for existing small businesses, restaurants, cafes, and centres offering cultural activities, to ensure accessibility for persons with disabilities.
- Require that newly-established businesses plan for and cater to the accessibility needs of persons with disabilities.

- Fund only public transport that is physically accessible to persons with disabilities and older people.
- For all public services and customer service for private companies, to require the possibility for assistance to be given by phone or in person (as promoted also by the [EU Accessibility Act](#)), rather than relying on digital solutions alone.

ENSURING ACCESSIBILITY THROUGH THE ACTIONS LISTED ABOVE WILL REMOVE SOME OF THE BARRIERS PREVENTING PEOPLE FROM ACTIVELY PARTICIPATING IN THEIR COMMUNITIES. IT IS ALSO A WAY OF FUTURE-PROOFING OUR SOCIETIES FOR AN AGEING POPULATION AND CREATING A MORE COMFORTABLE AND WELCOMING ENVIRONMENT FOR ALL, REGARDLESS OF AGE OR ABILITY.

Action 5

How to avoid expenditures that indirectly reinforce segregation

A. Funding for refurbishing institutional settings under the guise of improving energy efficiency must stop, as it simply extends the life span and operability of these care settings.

B. Avoid Funding of housing, reception centres, homeless shelters, refugee camps, etc. built in segregation/isolation from the community (for example, on the outskirts of towns or in sparsely populated areas). These are settings where persons with disabilities are overrepresented and discriminatory practices against them on the basis of disability must be eradicated.

C. Avoid funding in mainstream services which are not accessible for persons with disabilities (such as building schools not accessible to children with disabilities) as this will only increase demand for specialised services.

D. Avoid funding in congregated social housing (aimed at, for example, only people with disabilities, refugees etc.)

IT IS OFTEN NOT EASY TO SPOT THAT FUNDING OF THE KIND MENTIONED ABOVE WILL FURTHER THE SEGREGATION OF GROUPS SUCH AS PERSONS WITH DISABILITIES. HOWEVER, THEY SEVERELY UNDERMINE THE ABILITY TO FOSTER INCLUSION IN THE COMMUNITY AND MUST BE AVOIDED.

Action 6

How to better monitor improvements in the provision of personal assistance and inclusion in the community

A. Member States should keep and provide data on the number of institutionalised people, per target group, to the European Commission, and these should be made publicly available. They should, notably, start keeping track of:

1. The number of people using the newly-developed personal assistance, home care and other community-based services.
2. The number of newly-developed home care and other community-based services
3. The number of institutions closed down
4. The number of persons (e.g. children, persons with disabilities, persons with mental health problems, older people, homeless people) who moved out of the institutions to live independently in the community
5. The number of people deprived of their legal capacity
6. The number of children reintegrated with their families
7. The number of children placed in family-based care
8. The number of newly-developed housing options that support community living
9. The number of sheltered homeless people moved into permanent (supported) housing
10. The capacity of new or modernised social housing
11. The capacity of new or modernised social care facilities (providing non-residential services)
12. i. Data on the number of people in institutions should be updated on a yearly base and information on how the number has changed should be provided over a five years rolling period

B. Member States and local authorities should keep track of the demands for specific types of services in different areas (for example, the number of people requesting personal assistance) and the extent to which this outweighs availability. This monitoring of demand for and offer of different kinds of services should be used to decide where expenditures will be made going forward, to ensure that as many people as possible can receive the type of support they choose.

It is useful also to have an actual return on the number of people in institutions rather than just institutions themselves – and also ones that have been removed from institutions and are provided with new types of support.

Basis of the Guidance in EU Charters and International Conventions

The EU Charter of the Fundamental Rights

When implementing EU law, the EU institutions and the Member States are bound by the EU Charter of Fundamental Rights. This means that all EU funding should be used to protect and promote fundamental rights such as: respect for human dignity, the right not to be subjected to inhuman or degrading treatment, the right to liberty and security, the right to respect for private and family life, the right to education, the right to work, the right to health, equality and non-discrimination.

Furthermore, the EU Charter explicitly recognises the rights of those commonly placed in institutional care: children's right to protection and care according to their best interests (*Article 24*), the right of the elderly to live a life of dignity and independence (*Article 25*) and the right of persons with disabilities to participate in the life of the community (*Article 26*). Since people placed in long-stay residential institutions are denied many of these rights, such settings should not benefit from EU funding. Instead, any available funding should be used to support structural reforms aimed at the development of high-quality family-based and community-based services, the closure of institutions and on making mainstream services accessible to all.

The UN Convention on the Rights of Persons with Disabilities

In December 2010, the EU became a party to the UN Convention on the Rights of Persons with Disabilities (further referred to as “the CRPD”). By ratifying the CRPD, the EU has committed to ensuring that all relevant EU legislation, programmes and funding shall respect and promote equal opportunities for people with disabilities and the right to live independently and be included in the community (*Article 19*). The EU's 27 Member States have all signed and ratified the Convention as State Parties, meaning that their domestic policies and investment must also respect the rights enshrined in it.

Institutions exclude people with disabilities from society and prevent them from exercising their right to live included in the community. The EU and its Member States, within their respective competencies, have an obligation arising from Article 19 of the CRPD to remedy this situation and Structural Funds should be used as a key tool to comply with this obligation.

In addition to obligations arising from Article 19, the CRPD requires State Parties to ensure that people with disabilities are protected from any form of torture or cruel, inhuman or degrading treatment or punishment (*Article 15*); and from exploitation, violence and abuse (*Article 16*). Such treatment is a common occurrence in institutions across Europe.

As regards children with disabilities, Article 23 provides that they have equal rights with respect to family life; and where the immediate family is unable to care for them, State Parties shall “undertake every effort to provide alternative care within the wider family, and failing that, within the community in a family setting.”

The UN Convention on the Rights of the Child

The UN Convention on the Rights of the Child recognises that children, for the full and harmonious development of their personalities, should grow up in a family environment, in an atmosphere of happiness, love and understanding. The Convention has been ratified by all EU Member States, which are therefore required to take all appropriate measures to ensure, for children temporarily or permanently deprived of their family environment, special protection and alternative care, always taking into account the best interests of the child.

The UNCRC outlines a range of children's rights that, taken together, suggest that most children should live with and be cared for by their birth families (*Articles 7 and 9*). It is the primary responsibility of parents to raise their children and it is the responsibility of the State to support parents in order that they can fulfil such responsibility (*Article 18*). Children have the right to protection from harm and abuse (*Article 19*), to an education (*Article 28*) and to adequate healthcare (*Article 24*) but they simultaneously have the right to be raised by their family. Where their family cannot provide the care they need, despite the provision of adequate support by the state, the child has the right to substitute family care (*Article 20*) which should be subject to periodic review (*Article 25*)³.

The UN Guidelines for the Alternative Care of Children encourage governments to move away from institutions for children in a progressive manner towards family- and community-based care. MOVING FORWARD: Implementing the 'Guidelines for the Alternative Care of Children' sets out the reasoning behind the main orientations of the Guidelines and indicates legislative, policy and programming initiatives that should enable the provisions to be put into practice effectively.

Contacts

For further information about the guidance of the EEG regarding independent living and inclusion in the community, please contact us at coordinator@deinstitutionalisation.com

³ Mulheir, G. & Browne, K. (2007) De-institutionalising and Transforming Children's Services. A Guide to Good Practice. University of Birmingham: Birmingham.

⁴ Guidelines for the Alternative Care of Children : Moving-Forward-implementing-the-guidelines-for-web1.pdf (alternativecareguidelines.org)

