

Recommendation Paper: Deinstitutionalisation of persons with support needs and the use of the European Social Fund Plus (ESF+)

ESF Transnational Cooperation Platform

Community of Practice on Social Inclusion

Written by the European Association of Service providers for Persons with Disabilities June 2022

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1. Introduction

This recommendation paper on the use of the European Social Fund Plus (ESF+) for deinstitutionalisation of persons with support needs was developed as part of the work of the ESF Transnational Cooperation Platform (2020-2022)¹.

This paper addresses some of the specific objectives of the ESF+ under Article 4 of the regulation, in particular:

- "promoting equal access to and completion of quality and inclusive education and training, in particular for disadvantaged groups, from early childhood education and care through general and vocational education and training, to tertiary level, as well as adult education and learning, including facilitating learning mobility for all and accessibility for persons with disabilities;"
- "fostering active inclusion with a view to promoting equal opportunities, nondiscrimination and active participation, and improving employability, in particular for disadvantaged groups";
- "promoting the socio-economic integration of marginalised communities, such as Roma people;"
- "enhancing equal and timely access to quality, sustainable and affordable services, including services that promote the access to housing and person-centred care including healthcare; modernising social protection systems, including promoting access to social protection, with a particular focus on children and disadvantaged groups; improving accessibility including for persons with disabilities, effectiveness and resilience of healthcare systems and long-term care services; (I) promoting social integration of people at risk of poverty or social exclusion, including the most deprived persons and children"².

This paper solely reflects the initiatives and ideas discussed during the two events organised as part of the Community of Practice (CoP) on Social Inclusion by the ESF Transnational Cooperation Platform:

- a peer review on the transition from large scale institutional care to communitybased care, held in April 2021;
- a study visit on integrated support solutions (including supported housing), held in November 2021.

These activities reflected on approaches funded by the European Social Fund (ESF), in combination with other budgets, that support the transition from large-scale institutional care to community-based care, including supported housing, thus enhancing and promoting the

¹ The Platform comprises four Communities of Practice (CoP): 1) Employment, education and skills, 2) Social inclusion, 3) Results-based management, and 4) Social innovation. These CoPs enable ESF managing authorities (MAs), intermediate bodies, expert and sectoral stakeholders to exchange knowledge, practices and experiences, and to deepen cooperation. The Social Inclusion CoP promotes social inclusion and combating poverty in a holistic manner. It works to integrate marginalised communities, tackle discrimination, enhance accessible, affordable and quality community-based services, and promotes the social economy and community-led development strategies. The CoP focuses on three sub-themes: Poverty and Social Exclusion of Children, Deinstitutionalisation, and Homelessness.

² Official Journal of the European Union, REGULATION (EU) 2021/1057 OF THE EUROPEAN PARLIAMENT AND OF THE COUNCIL of 24 June 2021 establishing the European Social Fund Plus (ESF+) and repealing Regulation (EU) No 1296/2013.

process of deinstitutionalisation. It includes also key aspects for ESF+ funding, relevant for the general framework of programmes and their implementation through projects.

The paper is relevant for those managing or implementing the ESF, including managing authorities, intermediate bodies, relevant ministries, public bodies with responsibility for community-based care, stakeholders (in particular service users and providers), and relevant policy and desk officers in the European Commission. The key objectives of this paper are to:

- share lessons learnt and good practice from the activities of the ESF Transnational Cooperation Platform, thus increasing the possibilities to replicate deinstitutionalisation initiatives across the European Union (EU).
- provide recommendations on the future use of the ESF+ for deinstitutionalisation.

2. Why invest in deinstitutionalisation?

Across Europe more than one million children, persons with disabilities, persons with mental health problems, homeless persons and older people live in institutions³. Institutions are defined as any residential care where residents are isolated from the broader community and/or compelled to live together, do not have sufficient control over their lives and over decisions that affect them, and the requirements of the organisation itself tends to take precedence over the residents' individualised needs. These persons face social exclusion and poverty, although Article 19 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) clearly states the right to live independently in the community⁴. Thus, the transition from institutional to community-based care and independent living should be a priority on the national and EU policy agenda.

Deinstitutionalisation is defined by the United Nations Children's Fund (UNICEF) as "the full process of planning transformation, downsizing and/or closure of residential institutions, while establishing a diversity of other child-care services regulated by rights-based and outcomes-oriented standards."

Community-based care or community-based services is defined by the <u>EEG</u> (European Expert Group on the Transition from Institutional to Community-based Care as "the spectrum of services that enable individuals to live in the community and, in the case of children, to grow up in a family environment as opposed to an institution".

EU Structural and Investment Funds, including the ESF+, can support national, regional and local authorities in designing and implementing structural reforms aimed at the development of quality family-based and community-based alternatives to institutional care. To facilitate this, the EEG developed a checklist to ensure that EU funds in the 2021-2027 programming period contribute to independent living and inclusion in the community. Also, one of the flagship initiatives of the current European Strategy on the Rights of Persons with

³ European Expert Group on the Transition from Institutional to Community-based Care (2012, November). Common European Guidelines on the Transition from Institutional to Community-based Care. https://deinstitutionalisationdotcom.files.wordpress.com/2017/07/guidelines-final-english.pdf

⁴ Article 19 — Living independently and being included in the community | United Nations Enable. (n.d.). United Nations. https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-19-living-independently-and-being-included-in-the-community.html

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Disabilities (2021-2030) is the development of guidance towards Member States on independent living⁵.

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Directorate General. EMPL: Employment, Social Affairs and Inclusion. (2021, March 3). Union of equality: strategy for the rights of persons with disabilities 2021–2030. Publications Office of the European Union. https://op.europa.eu/fr/publication-detail/-/publication/3e1e2228-7c97-11eb-9ac9-01aa75ed71a1/language-en

Recommendations on the use of the ESF+ towards deinstitutionalisation

Below are recommendations from the CoP on Social Inclusion on the use of the ESF+ towards deinstitutionalisation:

Awareness-raising on the rights of persons with support needs and independent living



The whole community is concerned when it comes to independent living for persons with support needs: this concerns, first and foremost, the persons themselves and also their relatives, friends, all the professionals working in services supporting them, as well as staff members of mainstream services.

Communities need to be aware of the principles of independent living in order to facilitate the transition towards community-based care and support solutions. This requires awareness-raising with all relevant stakeholders in education, social, health care and leisure services. Ultimately, this aims to mainstream public services, such as health care, leisure activities or education, to be available and accessible to all. To do so, all relevant stakeholders should receive information and training about the principles underpinned in the UNCRPD.

Effective collaboration also requires work with families to enable them to trust the deinstitutionalisation process. Families, especially those families whose relatives have spent most of their lives in institutions, may be resistant to change and may not support the closure of large residential settings. Therefore, information and training sessions on the UNCRPD and deinstitutionalisation can strengthen their understanding.

In addition, working with families should start as early as possible, as early intervention is fundamental for the future development and social inclusion of children with support needs. Families of young children should thus be informed and supported and participate in the development of support plans.

Key aspects for ESF+ funding:

- Programmes should provide a strategic vision for awareness-raising in communities, and include a wider vision for family support, such as early interventions or support networks.
- Projects can implement this via public campaigns promoting the accessibility of mainstream services or non-segregated/inclusive education. This may also include involving families in awareness-raising sessions on deinstitutionalisation, informing them about choices and available support, or cooperating with them when implementing and monitoring rights to independent living policies and services.

Partnership principle for a holistic approach



Persons with support needs, families and informal carers and relevant civil society organisations should be actively involved in the planning, implementation and monitoring of the deinstitutionalisation process funded via the ESF+. Partnership working means action by the following actors to enhance independent living and to implement deinstitutionalisation: public authorities at the national, regional and local levels, and across sectors ranging from social care services to education and employment, housing,

health, and other sectors.

Hence, projects should ensure that all parties concerned can contribute and partnerships gather around establishing community-based care services. This enables a holistic approach that connects persons with support needs, their families, public authorities, mainstream services and support service providers and overcomes silos.

Key aspects for ESF+ funding:

- Programmes and actions should involve relevant stakeholders (service providers, professionals in educational, health and housing sectors, local governments, etc.)
- Project implementors should receive support (user-friendly information, advice) on how to access funds and to work in partnership.

Inspiring example: Deinstitutionalisation project in Greece

Greece, which was identified by the European Commission as one of the 12 Member States in need of deinstitutionalisation reforms⁶, has requested support from the European Commission regarding reforms of their social care system. EASPD (European Association of Service providers for Persons with Disabilities) was invited to assist Greece with this process.

The <u>DI Greece</u> project started in 2019 and ended in 2021. The project included a methodology for deinstitutionalisation, starting from a needs analysis and mapping, towards the development of a national strategy, an action plan, methodologies, procedures and monitoring tools for deinstitutionalisation (e.g. a needs assessment protocol, guidelines on support procedures in community-based care settings). This also included good practices from various EU countries which can be upscaled at national and international level. Although legal systems vary from one country to another, the main pillars of deinstitutionalisation remain the same.

Co-production for empowering support



Support should be planned based on the individual needs and choices of the person in need of support. Active involvement of service users, as well as the stakeholders evolving around them, will ensure a good transition towards community-based services. This type of co-production⁷ enables experts of experience (i.e. service users), family members, services

⁶ European Commission. (2019). Country Report Greece 2019. https://ec.europa.eu/info/sites/default/files/file_import/2019-european-semester-country-report-greece_en.pdf

⁷ See also: ESF Transnational Platform (2018) Co-production - enhancing the role of citizens in governance and service delivery https://ec.europa.eu/european-social-fund-plus/en/publications/co-production-enhancing-role-citizensgovernance-and-service-delivery

supporting them, civil society organisations and decision makers to come together and work towards the same aim; whilst empowering service users.

Key aspects for ESF+ funding:

- Principles of co-production need to be promoted in programmes, i.e. everyone has assets to bring to the deinstitutionalisation process. This goes along with the principles of diversity and accessibility and reciprocity which conveys an idea of mutuality, meaning that all stakeholders involved benefit from the deinstitutionalisation process and they are an integral part of its implementation and monitoring.
- Service users need to contribute to the design, implementation and evaluation of projects aiming to impact their lives: this ensures that the projects are indeed based on the service users' needs.

Inspiring example: Working with families and communities

In Finland the transition towards community-based living is in progress. At the end of 2019 there were 450 persons with intellectual disabilities living in institutions – a sharp decrease compared to 1 800 in 2010. In March 2012, Finland published a National Plan and Resolution on the Housing Programme for Persons with Intellectual Disabilities to provide individual housing for persons moving from institutions to ordinary living environments.

The Service Foundation for People with an Intellectual Disability (KVPS) implemented the programme for organising housing and related services for persons with intellectual and developmental disabilities in 2010–2020. This programme aimed at facilitating individual housing for persons with intellectual disabilities in ordinary living environments, thus reinforcing their social inclusion and equal treatment in communities and society. KVPS emphasised their work with family members as part of the deinstitutionalisation process. They set up workshops and discussions with service users and their families to consider what the best solution would be in terms of housing, thus ensuring self-determination, in line with the principles of the UNCRPD.

Staff training for person-centred and empowering support

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The transition to community-based care comes with the right awareness and mindset of independent living amongst professionals. Organisations and staff therefore need to adopt a human-rights based and personcentred approach for community-based care and support services.

However, some staff members might have doubts, so that balancing choice and control of individuals with protection and safety concerns may be challenging. Therefore, the shift towards deinstitutionalisation needs to be accompanied by a strong leadership commitment by service providers who can address fear by staff.

One key element is thus to provide staff with training to ensure understanding that community-based support requires often a shift of their own attitude towards their profession. This also includes awareness about the UNCRPD and how to implement it. In addition, staff need to know and use methodologies for providing person-centred support, like person-centred needs assessment, support for autonomy or offering an overview of different services available. Once re-skilled, they can best support persons with disabilities to move into the community.

Key aspects for ESF+ funding:

- Capacity-building and skills training for professionals working on community-based care should be foreseen in programmes and projects.
- Programmes need to foresee training initiatives to support life skills, autonomy, personal assistant training etc.

Inspiring example: the TOPHOUSE project

The Erasmus+ funded <u>TOPHOUSE project</u> aimed at defining and formally establishing the competences of professionals in the process of needs assessment, housing and support/care provision. The project was implemented by organisations from seven countries and developed good practices on integrated housing support and guidelines on individual needs and support for needs assessment. The project also developed a training package to train professionals in needs assessment methodologies, as well as core values of the UNCRPD.

These tools facilitate a dialogue between professionals and persons with disability based on co-production and individual choices and preferences.

Self-determination and representation



Setting up a self-advocacy group and peer support is essential to ensure that supported persons can express their needs and wishes. Also, family members and informal caregivers should be encouraged to support service users towards self-determination. This can be done via supported decision-making mechanisms which are a key tool for implementing the UNCRPD. This means that persons with disabilities may also work with a

support person, such as a mentor or personal assistant, to make their own decisions about their lives, thus ensuring their self-determination.

In addition, enabling legal frameworks, aligned with the principles of the UNCRPD, are a key element to achieve deinstitutionalisation. In that sense it would require to raise awareness at political level. This could be done via lobbying for the rights of persons with disabilities, enhancing their right for independent living and how these rights could be implemented.

Key aspects for ESF+ funding:

- Projects should promote self-determination, for instance via the creation of peer support networks, training on supported decision making, including also advice by experts by experience.
- Projects should encourage the hiring of support persons, such as personal assistants to support persons with disabilities expressing their needs (based on a supported decision-making approach). That goes along with the upskilling of personal assistants who would need to be aware of deinstitutionalisation and supported decision making.

Inspiring example

The Greek organisation Petagma, a service provider for people with intellectual disabilities, delivers supported housing services with and for service users. They offer supported living flats where persons with disabilities live in the community, with support based on their needs. While implementing these services, the organisation has identified some challenges,

such as the need for flexibility of services and the need for personal assistance to enable participation in the community. Furthermore, assessing the quality of life in community-based types of living is often not easy, which can be an obstacle to obtain funding.

Quality of life and quality of services



Independent living requires quality services enabling service users to make their own decisions and to be included in the community.

The quality of services contributes to and maintains a good quality of life for service users. Life and service quality should hence be included in quality and monitoring frameworks for services and could be promoted via national and international funded projects.

Key aspects for ESF+ funding:

- Promoting the implementation of national and international funded projects based on quality frameworks for services for persons with disabilities.
- Following the voluntary <u>European Quality Framework</u>, and upcoming EU Framework on Social Services of Excellence for Persons with Disabilities⁸ to ensure a consistency in service provision and rules between EU Member States.

⁸ By 2024 the European Commission will publish this EU Framework as communicated in the: Directorate General .EMPL: Employment, Social Affairs and Inclusion. (2021, March 3). *Union of equality: strategy for the rights of persons with disabilities 2021–2030.* Publications Office of the European union. https://op.europa.eu/fr/publication-detail/-/publication/3e1e2228-7c97-11eb-9ac9-01aa75ed71a1/language-en

Conclusion

Investing in services that foster a person-centred approach and co-production enables individuals to live independently, responding to their individual needs and wishes.

The ESF+ can be used to support in a number of areas such as: the training of personnel (to work in services that shift from institutional to community-based settings), creating employment opportunities in the community as well as technical assistance, e.g., assessment of needs and setting up a methodology to analyse the impact of the transition to community-based care.

With the ESF+, the transition from institutional to community-based care is recognised as a crosscutting issue. It is possible to create synergies between ESF+ and the European Regional Development Fund (ERDF) in order to have a more meaningful impact on the lives of service users. ESF+ and the ERDF can fund the upscaling of projects which then may be transposed into national legislation.

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