Conference on "Moving towards independent living and community-based care – EU funding instruments to support the development of community-based services"

Brussels, Belgium, 17 June 2019

Written by ICF and European Centre for Social Welfare Policy and Research and IRS

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1 Introduction

The European Commission and the European Social Fund (ESF) Transnational Platform hosted the Conference "Moving towards independent living and community-based care – EU funding instruments to support the development of community-based services".

The Conference brought together 80 representatives from Managing Authorities involved in the Thematic Network on Inclusion of the ESF Transnational Platform, as well as policymakers, service providers and civil society representatives from national and EU-level.

The conference represented an opportunity to discuss:

- The state of play and experiences of deinstitutionalisation (DI) from a European perspective and in two Member States (Austria and Croatia) ;
- Measures to support deinstitutionalisation: the use of personal assistance in Portugal, Estonia and Belgium as well as early interventions to prevent institutionalisation in France, Croatia and Portugal;
- Next steps to move away from institutional care to independent living and community-based care at national levels;
- EU funding instruments for the transition to community-based care and support in the future funding period.

2 Background and purpose of the conference

In 2018, more than one million children and adults lived in institutions across Europe[1], especially persons with intellectual disabilities or mental health problems. Moreover, a high number of people continue to (re-)enter institutional care despite deinstitutionalisation efforts.

Institutional care was once seen as the best way to care for vulnerable children and adults with disabilities and other support needs. However, evidence has shown that institutional care does not ensure the same level of autonomy, independence and life quality provided by community-based care. In the case of children, research has revealed that even a short period of institutional care can have long-term negative impacts on their brain development and emotional well-being[2].

Several legal[3] and policy initiatives[4] have been taken at EU and international levels to enhance the protection and promotion of the rights of children, persons with disabilities, the transition from institutional to community-based care and the prevention of institutionalisation of people in need of support.

[1] EU Fundamental Right Agency (FRA) report "From institutions to community living for persons with disabilities: perspectives from the ground (2018). Available at: https://fra.europa.eu/sites/default/files/fra_uploads/fra-2018-from-institutions-to-community-living-ground-perspectives_en.pdf

[2] European Expert Group on the Transition from Institutional to Community-based Care (EEG) "Common European Guidelines on the Transition from Institutional to Community-based Care" (2012). Available at: https://deinstitutionalisationdotcom.files.wordpress.com/2017/07/guidelines-final-english.pdf

[3] E.g. UN Convention on the Rights of Persons with Disabilities (CRPD), ratified by EU and all MS; UN Convention on the Rights of the Child (CRC); EU Charter on Fundamental Rights; European Convention on Human Rights; 2013 Commission Recommendation Investing in children: breaking the cycle of disadvantage etc.

[4] E.g. EU European Pillar of Social Rights; European Disability Strategy 2010-2020; EU Agenda for the Rights of the Child etc.

On the implementation side, under the European Semester, the European Commission monitors, besides the economic performance of Member States, also their progress in the social field, including also DI, through country reports and specific country recommendations. In addition, European structural and investment funding has been made available to support the transition from institutional to community-based care. In the current programming period, in 12 Member States, access to European Structural and Investment Funds (ESIF) was specifically conditioned to the fulfilment of ex-ante conditionalities on deinstitutionalisation, consisting in having a DI strategy in place.

In order to support Member States to better utilize available EU funding for the transition towards community-based care, the European Commission has promoted a cycle of capacity-building seminars between December 2018 and May 2019 aiming at:

- Improving the capacity of actors at local, regional and national levels to develop measures supporting the transition from institutional to community-based care and independent living, using EU funding instruments;
- Supporting the capacity of people with support needs, in particularly marginalised groups, to take an active part in designing support and services in the community.

The conference in Brussels was the final event of this cycle of capacity-building seminars that took place in Austria, Croatia, Romania and Slovakia.

The conference aimed to build the capacity of EU and national public and social actors, including people with support needs, by facilitating a transnational exchange on independent living and community-based care, with a focus on how to overcome barriers to deinstitutionalisation.

3 State of play of deinstitutionalisation in Member States

The debate on the state of play of deinstitutionalisation in Member States has shed light on the fact that deinstitutionalisation exists in both Eastern and Western Europe. This situation is also due to the lack of a common understanding of deinstitutionalisation and its overall objective, namely to fully include all targets groups in society via a person-centred and human rights-based approach.

In all Member States, deinstitutionalisation entails a change in the paradigm adopted to social care. It means moving away *from the institutional culture approach* which was based on:

- the isolation of people with support needs;
- the consideration of the interests of the institution above those of the person;
- limited choice and control over decisions affecting his/her own life;
- the rigidity of the daily routine; and
- lack of real alternative care, forcing people to live in institutions.

Instead, *the community-based care approach* aims to bring support closer to people, ensuring that they live independently in the community, allowing them to realise their potential fully and to live a life with dignity.

Transition from institutional to community-based care consists of creating an overall inclusive society in all its aspects, including housing, education, employment and health care.

However, several interlinked obstacles hinder the deinstitutionalisation process in Member States. The persistence of institutional culture in the mindset of society, reinforces the perception that institutions are the best solution to provide care. Opposition to the community-based care transition from medical professionals and families of people with support needs is frequent. As a result, there is uneven pressure on politicians to take fully on board deinstitutionalisation programmes.

The lack of continuous political commitment represents another obstacle to deinstitutionalisation, as it prevents the adoption of a long-term vision for the transition to community-based care. Also, target groups' limited involvement in the deinstitutionalisation policy process, may result in measures that are not shared -if not even contested- by the final beneficiaries.

Moreover, even when DI policies are adopted, the limited horizontal and vertical cooperation between actors from different sectors (such as education, housing, labour market, health, transport) might result in fragmented or inconsistent initiatives. Limited provision and scattered geographical coverage of community-based services does not make deinstitutionalisation accessible to all potential beneficiaries and favours continuous (re)institutionalisation.

Finally, the development of innovative practices is often stifled by the limited flexibility of service providers and the lack of knowledge and skills of actors involved in the deinstitutionalisation process.

The paragraphs below provide details on DI for specific target groups in each of the above-mentioned country.

3.1 Deinstitutionalisation of homeless people in Austria

Homelessness is an urban phenomenon. Despite the prevailing prejudice, associating homelessness to misconducting, the two of the leading causes of homelessness in Vienna are the increasing costs of housing and the long waiting periods to access affordable social housing.

Traditionally homelessness has been tackled in a paternalistic way, implying that people should be prepared before receiving a home. Nowadays, this traditional model has been challenged. Evidence shows that all persons are able to live independently with adequate community-based support. Housing is increasingly recognised as a human right. A new approach has been adopted to dealing with homelessness in Austria: the so-called *Housing First* approach[5]. It is based on human dignity and independent living, according to which anybody is capable of living on his or her own in permanent accommodation with the right support.

The following factors enhance the effectiveness of this approach:

- The involvement of homeless persons in the decision process;
- Strong collaboration between social workers, landlords and the homeless person;
- Promotion of a cultural shift in the way care is provided which should be based on the freedom of choice of the homeless person, collaborative development of rules, flexibility and customisation of arrangements and right to privacy;

[5] For more details on this approach, see Sina Lipp, "State of Play: Deinstitutionalisation of homeless assistance services in Austria" (2018) available at: http://ec.europa.eu/esf/main.jsp?catId=68&langId=en&eventId=1410

- An attractive and central location of apartments, avoiding concentration of social housing only in suburbs;
- A consistent legal framework.

The Austrian experience shows that cooperation arrangements between the housing department and social department should be in place to prevent the (re)institutionalisation of homeless people. Furthermore, a nationwide binding action plan, whose implementation is feasible at the local level[6], should be adopted. Permeable and permanent access to social housing is also necessary to avoid institutionalisation of homeless people. Lastly, consistent monitoring of homeless persons should be ensured.

3.2 Deinstitutionalisation of children without adequate care in Croatia

Since 1990, the Croatian authorities have been working to transition toward community-based care for children without adequate care with uneven results. With the start of the negotiations for the adhesion to the EU and the ratification of the UN CRPD, the process accelerated and a specific Plan for deinstitutionalisation[7] was adopted in 2011. While still not fulfilling the target set by the Plan, the number of children living in institutional care has decreased by 71.6% since 2015. As of August 2018, 814 minors were still accommodated in institutions and many others continued to re-enter in the system.

The Croatian DI process has been facing several challenges in the last ten years:

- lack of change of the paradigm on how to ensure care for children without parental care. This was coupled with the persistence of a culture promoting institutional care over community-based one.;
- lack of continuous political commitment on DI, combined with limited knowledge and skills on how to effectively implement it in practice;
- unbalanced geographical distribution of community-based care services;
- shortcomings of the foster care system, coupled with a lengthy adoption process;
- lack of a strategy for strengthening families and children at risk;
- long delays in the implementation of European structural and investment funds (ESIF) calls in this area, resulting in limited use of EU funds available
- unequal access of civil society organisation to funding compared to state institutions.

- The DI experience in Croatia shows that in order to ensure an effective transition from institutional care to community-based care, the following issues should be considered:
  - framing the transition as a comprehensive process, mainstreamed in all policies and legislative measures relevant for its achievement;
  - designing specific strategies and legislation in this area;
  - actively involving target groups (children, families, etc.) and ensuring strong collaboration between all actors involved, including also civil society organisations;

[6] In Austria, tackling homelessness is a task of the Länder.
[7] For more details on the Plan and on the deinstitutionalisation process in Croatia, see

- adopting preventive measures to strengthen the capacity of families/foster carers in risk and preventing (re)institutionalisation;
- ensuring a geographically balanced provision of community-based care services, coupled with the adoption of quality standards;
- monitoring the use of EU funds in this area combined.

3.3 European perspective on deinstitutionalisation of persons with disabilities

The FRA report (2018) "From institutions to community living for persons with disabilities. Perspectives from the ground" presents a European overview of the process of transition from institutional to community-based care in five Member States: Bulgaria, Finland, Ireland, Italy and Slovakia

The analysis shows that many persons with disabilities continue to live in institutions in these countries and therefore do not have full control over their own life and decisions. Community-based services remain largely insufficient and often inaccessible. Moreover, for those persons with disabilities living in the community, support with daily living tasks is not enough.

The research reveals that barriers to deinstitutionalisation are common across the five countries. Namely, they are:

- The persistence of institutional care models, which triggers also learned dependence of persons with disabilities and family resistance to the transition from institutional to community-based care;
- lack of horizontal and vertical intersectoral cooperation;
- insufficient guidance on how to implement deinstitutionalisation, especially at local level, coupled with insufficient preparation and information to persons with disabilities and their families/tutors;
- inaccessibility of mainstream services and support services at the community level;
- lack of employment opportunities for persons with disabilities that could support their independent living;
- deprivation of legal capacity;
- the rigidity of rules and regulations on service provision contrasting with the need for support customisation to enable persons with disabilities to live independently;
- limited funding which is difficult to access and unequally distributed.

Based on the analysis of the transition to community-based care process, the research identifies several drivers for ensuring the independent living of persons with disability.

The promotion of a cultural shift in the approach to deinstitutionalisation coupled with long-term political commitment is of paramount importance in pushing the process forward. In addition, the adoption of evidence-based DI strategies foreseeing adequate funding, clear timeframes and benchmarks can favour a long-term commitment.

The development of horizontal, vertical and intersectoral cooperation mechanisms (e.g. specific committees, coordination measures, etc.) together with the adoption of participatory approaches in all phases of the deinstitutionalisation policy process are equally important.

Actions that redefine perceptions -such as individual stories, awareness-raising campaigns, testimonials- can be useful for both fostering this shift and putting the transition to the community-based care on the public agenda.

Overall, the transition from institutional to community-based care can occur only if there is a geographically balanced development of a qualitative, accessible and wide range of community-based living arrangements and service provision. Increasing flexibility in the provision of community-based services is also important to cater to the diverse needs of people with disabilities.

Adequate funding is crucial to ensure sustainability of the process of transition from institutional to community-based care. Thus, building synergy between ESIF and national resources is necessary. Equally important is to monitor that the allocated resources are actually invested in the creation of community-based care services and not in refurbishing old institutions, or in creating simply smaller institutional type of settings.

Collection of reliable, comparable and timely data disaggregated by type and severity of disability is also important for pushing the transition process forward.

4 Measures to support and prevent institutionalisation: the use of personal assistance and early interventions

This session provided insights on two types of measures supporting the transition to independent living and prevention of (re)institutionalisation: the use of personal assistance and early interventions. Practices implemented in Portugal, Estonia, Belgium, France and Croatia were presented during the conference.

Presenters acknowledge that an **effective personal assistance model** is characterised by the following features:

- the right to receive funding for all persons in need of personal assistance irrespective of their level of disability or capacity to work;
- funding provided directly to the beneficiary and not to the service provider;
- no restriction to support services funded by the PA scheme;
- services tailored to the needs of beneficiary designed through a shared dialogue between the user and the service provider;
- beneficiaries' control over the organisation of the services provided and of the personal assistant.

The practices discussed have shed light on the challenges faced in particular by the PA model in the implementation phase, such as:

- low level of resources allocated to the scheme, which limit it to specific categories of beneficiaries;
- fragmentation of competences of public institutions. For instance, some support services might be under the responsibility of local authorities, while others under regional/national institutions;
- limited integration of support services in the social and healthcare area;
- uneven allocation of resources for support services.

The practices presented have also provided insights into the main factors that could foster the effectiveness of both PA and early interventions.

- Adoption of a participatory approach to designing solutions fit for users' needs; understanding and overcoming potential obstacles in the delivery phase. This will also ensure a stronger social legitimacy of these solutions;
- Creation of a single-entry contact point for services and adoption of a case manager. These measures will simplify their access;
- Provision of community-based care services that are geographically close to the beneficiary. These services should be person-centred and focused on prevention.
- Building the capacities of family carers and other professionals involved in the delivery of personal assistance and early interventions to ensure high quality of the care provided;
- Development of peer groups to allow exchanges of experiences and learning between carers (both professional and familiar) can enhance the capacity building process;
- Existence of a certain level of community resources (financial, knowledge, etc.) to support the development of interventions.

4.1 The use of personal assistance in Portugal

Personal assistance (PA) in Portugal is tested through a pilot project implemented in five areas (Lisbon, Algarve, North, Center and Alentejo). PA targets persons aged at least 16 years old with a certified level of disability of at least 60%. However, persons with intellectual disabilities, mental health problems, or persons on the Autism Spectrum can accede to the measures irrespective their level of impairment. PA gives access to support services for the daily life of the beneficiary, ranging from hygiene, food, personal care, domestic assistance to travelling, culture, leisure, sport, employment or vocational training.

The "Centros de Vida Independente" (CAVIs) are in charge of the promotion of PA and some of them are created by the beneficiaries themselves. Thus users have a key role as they participate in all steps of the system, including the development of the individualised plan or the selection and management of the personal assistants.

"Professional" personal assistants provide care services. They cannot be related to the beneficiary and have to be contracted by CAVI and paid 900 euro for 40 working hours/week. The personal assistant can work for more than one beneficiary.

According to the representative of one of the CAVI, the limited budget allocated to the PA scheme (EUR 1 200 000) hinders the capacity to reach a wide range of people in need of support. It also limits the effectiveness of the measure, as sometimes the limited budget might reduce the number of PA hours allocated to the beneficiary.

4.2 The use of personal assistance in Estonia

Initiated in 2006, the DI process has brought a shift from institutional to community-based care. In 2017, an ESF funded project for piloting DI at the local level was implemented in 8 local governments. Its goals were trifold: to assess the level of preparedness of local governments; to organise community-based care services; and to integrate social, employment and healthcare services. The project puts persons at

the centre of the system and encourages tailor-made solutions. It integrates various types of services[8] and pays particular attention to personal assistance.

Personal assistance is provided based on the assessment of the beneficiaries' need for support and their capacity to work.

The Estonian experience shows some interesting success factors that should be considered in the design and implementation process of DI:

- integration of the social and healthcare services which changed in their focus from consequences to prevention;
- development of crises-interventions in social and healthcare sectors also by integrating their funding;
- role of the social worker as a single entry point in the system and case manager.

4.3 The use of personal assistance in Belgium: impact on the career choice of relatives of persons with disability

Since 2017, Belgium has introduced personal budgets for adults. Beneficiaries receive money/vouchers for purchasing personal assistance and other support services provided in the community. The system will be available for minors from 2020 onwards.

The Belgian system foresees that the beneficiary employs personal assistants who can also be their relatives. As a result, there is already some impact on the career choice of family carers. For instance, many mothers have resigned from their jobs to act as personal assistants for their children.

In this context, the ESF transnational project "Personal assistant: to be or not to be" aims to support families of persons with disabilities to make an informed decision when confronted with the choice of becoming or not a personal assistant.

Two main success factors have ensured the effective implementation of the project: the co-creation of the tools with persons with disabilities and their families/relatives and the engagement of government, professionals and self-organisations from the start.

4.4 Early interventions in France: RePairs Aidants – supporting family carers

In a context of limited resources, ageing of the population and deinstitutionalisation, family carers have become real economic players and essential care providers. However, there is a risk of transferring national solidarity to families, without providing them with adequate support and without providing qualitative services to persons with disabilities, elderly or sick people.

In this framework, the project aims to increase awareness on the role of family carer and the right to the free choice of this role as well as to support family carers' self-determination. The project consists of an awareness training co-facilitated by a family carer and a professional caregiver, which analyses family caregiving.

[8] E.g. rehabilitation, assistive technology, translation services, social transport, sheltered work, support at home or in small units and their adaptation, support for families, etc.

The initiative has been positively assessed by family caregivers. Some of the caregivers involved in the training have set up an advocacy group to work on the rights of family carers.

The main success factors of the initiative consist of:

- adoption of a participatory approach to the development and management of the programme, by actively involving both carers and professionals;
- promoting exchanges of experience among family carers through support/peer groups also by using participatory methods (testimonies, storytelling, co-animation of training sessions, etc.);
- provision of replacement in care to allow family carers to attend the session;
- quality of the training team;
- multichannel communication to reach out to family cares effectively.

4.5 Early interventions in Croatia: One Moment project

The ESF funded "One moment" project aims to improve the support provided to children and young people with behavioural problems and without adequate parental care. It also offers support to their foster carers to sustain their life in the community.

The project targets 50 children and youth, 5 families and 25 experts over the three years of implementation.

It consists in the provision of deinstitutionalisation services, including also early intervention to prevent institutionalisation. The project also offers counselling of families at risk, mobile teams to provide services closer to the users, organised living in small family houses units. Furthermore, it foresees training and study trips in other EU MS to increase the capacities of professionals.

The main success factors of the project include:

- bringing care services closer to the users;
- quality of the professionals in the community care area;
- attention to the continuous improvement and innovation of services provided;
- transition from treatment to therapeutic work.

4.6 Early interventions in Portugal: Senior club initiative

The Senior club targets 50 users aged over 65 years with the aim to promote their active and integrated ageing in community. In order to be part of the club, senior citizens should preserve their physical capacity and independence; live in the Western part of Lisbon; and enjoy living, learning and teaching. To be admitted, senior citizens need to undertake a an interview and there is a probation period. Almost half of the club users are subsidised, while the others pay a fee based on their level of income.

The Club promotes several activities: information and awareness, physical/motor activities, leisure and cultural activities, intergenerational support activities, volunteering and active participation in the decision process of the Club.

The Club has achieved relevant results: i.e. 94% of the users sustain that participation in their club activities has improved their quality of life.

In order to be replicated particular attention should be paid to the following aspects:

- quality of the venue of the club and the professionals employed by the club;
- efficient spending of the available resources.

5 Next steps to move away from institutional care to independent living and community-based care at transnational and national levels

This chapter draws on the findings of two workings groups implemented during the event:

- the first working group focused on the measures to be taken at EU, national and civil society levels in order to move forward with the transition to community-based services;
- the second working group focused on how transnational project can move deinstitutionalisation process forward.

The paragraphs below detail the main measures proposed by participants in these working groups.

5.1 Measures at EU, national and local level to move forward with the transition to community-based services

5.1.1 Measures at EU level

Sharing a common understanding and vision of deinstitutionalisation at EU level is considered essential for ensuring that transition to community-based care is coherent and consistent across Member States. According to participants in the working group, this can be achieved by verifying the coherence of national approaches to DI with EU guidelines in this area as well as though international legal and policy framework.

In order to avoid a silos approach to deinstitutionalisation (i.e. focus on specific targets or components of the process), participants suggested that the *transition to community-based care should be mainstreamed in all EU policies and programmes*. In addition, according to participants, the adoption of a standard approach to deinstitutionalisation within EU funds (e.g. AMIF – DI of migrants) is equally necessary for its full achievement.

Ensuring adequate and sustainable funding to transition to community-based care is another crucial issue pointed out by participants. EU institutions should strengthen funding allocated to organisations which provide community-based care services. Furthermore, they should negotiate the allocation of funding to DI with Member States. This should also include measures for ensuring its sustainability throughout the programming period. In addition, grants for the participation of DPOs and CSOs in the monitoring of ESIF in the field of DI should also be available at EU level.

Adopting collaborative processes (co-design, co-production, co-evaluation) to develop, deliver, monitor and evaluate interventions in this area is important, in participants' view, both at EU level and national level. Participants underlined that EU institutions can enhance the adoption of such approaches at national level through specific grants foreseeing the involvement of DPOs and CSOs in the monitoring of ESIF.

Raising awareness and building capacities on transition from institutional to community-based care of actors involved in this process is another point raised by participants. Awareness-raising and capacity building initiatives should also be targeted to EU staff in this area. Equally, particular attention should be paid to promoting transnational (EU) awareness-raising campaigns to EU citizens on independent living and community-based services.

Learning from the experience of other EU MS was particularly valued by participants in the working group. Therefore, specific funding programmes (e.g. similar to EQUAL) with a lean administrative procedure should be available at EU level for supporting mutual learning, exchanges of experience processes and for bridging local good experiences.

In order to strengthen the effectiveness of deinstitutionalisation measures, participants suggested *adopting a payment by result approach* at the level of EU MS for ESIF projects funded in the field of DI, while ensuring the quality and compliance of the services with international human rights standards.

5.1.2 Measures at national level

Ensuring sound and inclusive processes from planning to monitoring is considered a crucial measure for the effectiveness of the process at national level. In order to achieve it, Member States should adopt a participatory approach to the planning, delivery and monitoring of interventions in the DI area through the active involvement of public and private actors at various territorial levels. In addition, they should exploit the planning moment to create trust among the various actors and cement an agreement on the values of the DI process.

In participants' view, creating a sound and inclusive deinstitutionalisation process requires a long-term political commitment and allocation of funding. The drafting of a programmatic document (Strategic/action plan) on DI, including responsibilities, funds, sequencing of initiatives and clear outcome indicators can favour long-term commitment. This document should also allow monitoring of implementation against the set targets. Monitoring of the use of funds in this area should involve stakeholders, including also international organisations, (e.g. Committee on the Rights of Persons with Disabilities).

Strengthening horizontal and vertical coordination is another relevant measure pointed out by participants to break the silos approach and minimise regional inequalities in community-based care services and in particular in their quality level. In developing coordination mechanisms, particular attention should be paid to supporting the coordination of services providers (e.g. through the creation of specific networks). According to participants, this could also ensure a bottom-up pressure to local and central authorities. *Fostering awareness raising and building capacities* is required also at national level to enhance the cultural shift to promote the most adequate form of care for people in need of support. For instance, campaigns addressed both to the general public and communities to tackle the stigma around the people leaving/living in institutions should be promoted. In addition, awareness-raising campaigns and capacity building should also target all kinds of service providers.

Continuous improvement in community-based care services and scaling up of innovations in this area are also important for pushing forward the deinstitutionalisation process. According to participants, a mapping of existing services (and their absence) to highlight promising and tried-and-tested practices that can be scaled up at the national level should be undertaken. The mapping should not be limited to social care, but should also take into consideration other sectors (e.g. housing) as well as prevention services, paying particular attention to support offered to families. With regards to this latter point, in participants' view, the role of families in providing informal care should be acknowledged and families should be provided with respite and other forms of financial and non-financial support.

Furthermore, funding should be available for piloting new approaches and services to ensure the transition from institutional to community-based care.

5.1.3 Measures to be implemented at civil society level

Measures to be promoted at civil society level are quite similar to those foreseen at EU and national level.

In order to push deinstitutionalisation forward, a *common understanding of its principles and values should be in place.* This should allow for bridging different target groups and for ensuring that all target groups are considered in the process. In addition, it should also contribute to promoting a stronger demand for DI.

A *stronger coordination* is not only needed between institutions and service providers, but also among civil society organisations. According to participants in the working group, developing stronger communication and coordination mechanisms between NGOs (e.g. through networks, peer learning, etc.) can contribute to bridging experiences, providing learning on good practices and avoiding duplication of already existing initiatives. In addition, enhanced coordination between NGOs from different fields can favour the adoption of a comprehensive approach to deinstitutionalisation that takes into consideration all the needs of persons subject to or at risk of institutionalisation.

Moreover, stronger cooperation and coordination between civil society organisations can trigger an increase in the access to funding, in particular of small ones.

According to participants, civil society organisations should *support the implementation of sound and inclusive deinstitutionalisation processes* through:

- empowering self-advocacy groups of persons subject to DI or at risk of institutionalisation to enhance the demand for independent community living;
- acting as watchdogs of initiatives implemented in the DI area, including of those funded by ESIF to ensure delivery of effective DI projects coherent to the international principles at the basis of DI. This can also put pressure on politicians to commit to effective DI.

In addition, participants underline that civil society organisations have a crucial role in *fostering awareness raising and building capacities on transition from institutional care to community-based care.* In participants' view, civil society organisations can increase awareness on the advantages of deinstitutionalisation for both persons in need of support and society through:

- praising its cost-effectiveness;
- giving voice to deinstitutionalised persons (storytelling of success experiences);
- implementing media campaigns against discrimination and stigmatisation;
- communicating the DI vision and facts and evidence in this area.
- As many of the civil society organisations existent in this area are also service providers, they should pay particular attention to *developing mainstream services* adapted to the needs of people at risk of institutionalisation (e.g. persons with disabilities) in order to prevent their institutionalisation. *Continuous innovation of services provided,* also through the use of new technologies, is considered equally important for pushing the transition process forward.

5.2 Transnational collaboration: some ideas

Several project ideas have been promoted during the meeting, such as:

- Creating a network of experts involved in DI at national level for learning and supporting authorities in charge of DI in its planning and delivery;

- Developing common standards for independent living, including also an individual needs assessment of DI target groups, and their dissemination;
- Using the Erasmus programme for exchanges relating to independent living in order to support public institutions to deliver DI through co-production approaches;
- Exchanging practices between institutions and stakeholders in different countries to enhance learning on how to plan and deliver effective DI;
- Supporting care leavers to live independently, through active participation, peer learning, financial support, access to housing and mentoring;
- Enhancing the transition to adulthood of care leavers through capacity building, development of support services and the promotion of exchanges between young people transiting to adulthood;
- Promoting peer-based exchanges to empower self-advocacy groups, support authorities in the delivery of DI and design standards in this field;
- Building a sustainable approach to DI through the provision of learning on good practices, the development of a DI sustainability roadmap and capacity building;
- Creating a European Center for Family Quality of Life to enhance cooperation and mutual learning of public staff, stakeholders, practitioners and beneficiaries of DI and to support long-term funding.

6 European Structural and Investments (ESIF) funds supporting the transition from institutional to community-based care

Over the years, ESIF has been decisive in enhancing the transition from institutional to community-based care. However, enhanced synergies between ESF, ERDF and national funds are needed, also in view of sustaining community-based care and support for independent living on national budgets.

In the current programming period, ESIF can be used to progress towards deinstitutionalisation and independent living. According to ESIF regulations, EU MS should allocate 20% of their ESF funds to the promotion of social inclusion as foreseen in the Thematic Objective 9, which encompasses also the shift from institutional to community-based services.

In this programming period, EU MS can support DI through 'soft measures' (e.g. job creation) funded by ESF and hard measures (e.g. social infrastructure) financed by ERDF.

The European Commission's proposal for the next Multi-Annual Financial Framework 2021-2027 foresees that EU funding will be provided under the thematic objective "A more Social Europe" (the European Pillar of Social Rights) and implemented in particular through the ESF+ and the ERDF as well as other programmes such as EUInvest and Horizon Europe. The European Pillar of Social Rights includes a series of principles relevant for deinstitutionalisation:

- childcare and support to children,
- inclusion of persons with disabilities,
- long-term care and healthcare,
- housing and assistance for the homelessness,
- access to essential services

- education, training and life-long learning
- healthy, safe and well-adapted work environments.

ESF+ will support the delivery of the European Pillar of Social Rights through the provision of 101,2 billion Euro allocated mostly to the creation of jobs and active inclusion. ESF+ supports the transition from residential/institutional care to family-based care (recital 18). It provides access to quality, sustainable and affordable services (art. 4). Furthermore, it promotes equal opportunities and non-discrimination, including also in the transition from residential to family and community-based care (art. 6 of the General provisions).

The proposed ESF+ shared management strand will earmark at least 25% of the funding for social inclusion, 2% to tackling material deprivation and 10% to supporting youth not in education, employment and training (NEETs).

The ESF+ direct management strand will focus on employment and social innovation (761 million Euro) and health (413 million Euro), which may also contribute to deinstitutionalisation efforts.

However, the ESF+ framework is still subject to negotiations between the European Commission and the Member States.

The ESF+, and more in general Cohesion Policy funding, will be strongly aligned with the European Semester and, hence, the Country Specific Recommendations. Furthermore, ex-ante conditionalities[9] will be replaced by the enabling conditions. This change will ensure that all necessary institutional and strategic policy arrangements for the effective and efficient use of European Structural and Investment Funds will be evaluated before funding is released to Member States and also monitored throughout the entire programming period.

The next programming period will likely be characterised by an increased focus on 'payment by results' to simplify the administration of the projects financed under ESIF. The Partnership Principle, requiring all stakeholders to be involved throughout the programming in the planning, implementation and monitoring of EU funds, will be enhanced and will help to ensure the quality of project outcomes as well as compliance with human rights standards. Another important element of the Multi-Annual Financial Framework 2021-2027 is that residential care units, irrespective of their dimension, cannot be funded. This proposal is meant to prevent a shortcoming of the current programming period, when EU funds have been used for moving people from large-scale institutions to smaller institutions, or to finance the renovation of large-scale institutions.

7 Conclusions

Despite the decisive role of ESIF in fostering progress in this area (e.g. closing of several institutions and development of community-based services across EU MS), institutional care continues to exist in both Eastern and Western EU MS.

In many countries, institutional care model continues to dominate, despite evidence on the benefits of deinstitutionalisation and community living for both beneficiaries and the community. Furthermore, there is often no common understanding of deinstitutionalisation and its overall objective.

Transition from institutional care to community-based care is also challenged by limited long-term political commitment to this objective, which hinders sustainable

[9] EX-ante conditionalities refer to ensuring that all necessary institutional and strategic policy arrangements for the effective and efficient use of ESI Funds are in place before funding is released to Member States.

financing of DI. The limited horizontal and vertical coordination of actors involved in the process prevents the adoption of a comprehensive approach to DI.

The stakeholders' and beneficiaries' limited engagement in the DI process reduces decisions makers' capacity to take stock of their knowledge in this field.

In addition, there is often limited knowledge and skills in newly created community-based services. Such services are more common in bigger cities and towns, which can rely on a certain amount of resources. Rural and more remote areas often do not have such services in place.

Several measures can be implemented to overcome these obstacles to the transition from institutional to community-based care:

- *Acknowledging that deinstitutionalisation of people with support needs is an EU-wide problem*

Recognising that DI is an EU wide problems that should be tackled at both EU and national levels.

- *Setting a Europe-wide vision of the deinstitutionalisation process*

The EU vision to DI has to be embedded in the promotion and respect of human rights. Deinstitutionalisation is not only about closing institutions, but about transforming the way care and support are provided in the full respect of human rights, autonomy and social inclusion. Transition from institutional to community-based care is about creating an overall inclusive society in all its aspects, including housing, education, employment and health care. It requires the systemic transformation of the way care and assistance for people with support needs are perceived and provided.

- *Creating solid governance and legal framework in this field*

Political commitment is crucial to ensure the sustainability of the transition to independent living over time. Designing specific long-term strategies, including clear objectives, actions and time frame, division of responsibilities, allocation of resources and participatory monitoring and evaluation mechanisms may strengthen the commitment of politicians towards linear development of deinstitutionalisation over time. It is important to ensure the adoption of collaborative approaches and coordination mechanisms of actors involved throughout the delivery, monitoring and evaluation phases of the process.

An appropriate legal framework to implement measures fostering independent living is essential to make authorities and service providers in charge of the deinstitutionalisation process accountable.

- *Raising awareness and building capacities*

In order to successfully implement the transition from institutional to community-based care, a cultural shift in the way society perceives and cares for people in need of support is necessary. Awareness-raising campaigns showcasing success stories of people benefiting from community services should be promoted as they can contribute to changing the mindset of the society in general. The involvement of persons with support needs in these types of activities is useful for breaking stereotypes and establishing more user-friendly services.

- *Creating inclusive societies*

Inclusive societies can only be created if mainstream services are accessible, available and affordable to all citizens, including people in need of support.

This entails taking into consideration the needs of different target groups in the design and delivery of services. Particular attention should be paid to groups with multiple

risks as well as to groups that could be potentially left out of deinstitutionalisation efforts.

The involvement of people in need of support and of their families in the design and delivery of these services can help to make them truly person-centred. Social innovation, assistive technology and devices can play an important role to support people with different support needs living in their own home and receive support there.

Furthermore, in order for the transition process to be completed it is crucial to put equal efforts in preventing persons from (re-)entering institutions through specific services. Moreover, it is important to ensure the sustainability of the community-based services through adequately financing their operational costs.

- *Strengthening monitoring and evaluation of the transition from institutional care to community-based care*

The transition from institutional care to community-based care should be carefully monitored and evaluated against quality standards. This implies designing clear outcome indicators and adopting a participatory approach,

Data collected through monitoring and evaluation should be reliable, comparable and timely in order to ensure benchmarks of the transition process at local, regional, national and EU level. In addition, it should be disaggregated by gender, age and type and level of support needed.

Annex I: Working group 1 - "Next steps to move away from institutional care to independent living and community-based care"

1. What measures should be taken at the EU level to move away from institutional care to independent living and community-based care?

- The EU level should provide **definitions and process guidance** to Member States. The different understandings on the deinstitutionalisation process should be verified across the countries to make sure that they share a common ground. A Communication of the European Commission on the transition from institutional to community-based supports would be a useful tool;
- **Transition should be mainstreamed** in all EU policies that may be relevant to DI. Moreover training should be provided to the European Commission's staff (policy officers/desk officers) in order to improve their understanding of deinstitutionalisation;
- Transnational programmes should be **simplified**. At the moment, the procedures are too complicated for potential partners. The calls should be clear and the approval process in the Member States should be streamlined. The payments should be staggered and based on checks whether projects are well-implement. Tick-box evaluations years after the projects are closed should be avoided;
- **Awareness-raising** activities should be carried out both at EU and national level. This should include exchange of good practices and showcasing of examples at the local level, also across sectors to break the logic of the silos;
- The European Commission should negotiate a long term-commitment with Member States to provide national funding once the European funding is over, in order to ensure **sustainability**;
- **Standardised approaches** should be set up through funds;
- **Monitoring** of the progresses, of the sustainability and of the use of the funding should be carried out; this element could be included in the CSR or in the Country reports. DPOs and CSOs should also be included in the monitoring exercise. Funding should be granted for these monitoring activities, as an action. As regards the monitoring committees of EU Funding, their composition and activities should be made more transparent;
- **Human rights-based trainings** on community-based care should be carried out in schools, and particular in VET and higher education to sensitise future staff.

2. What measures should be taken at the national level to move away from institutional care to independent living and community-based care?

- **Prioritise** and identify which measures should come first. The planning should be very clear. NGOs, people with disabilities and stakeholders should also be involved in the planning and in the preparation of a concrete strategy/action plan. The process designed should not exclude certain groups (e.g. migrants, refugees);
- Recognise that community-based care can be **financially sustainable**;
- Enhance **inter-ministerial cooperation**. The creation of an inter-ministerial body working specifically on DI could be a good idea;
- Involve **local authorities** and adopt a local approach to project implementation;

- **Families** should also be involved in the process and adequately supported. They should be considered as an accelerator for recovery;
- Organise activities to **increase the understanding** of community-based care, such as training for care professionals;
- Move away from a medical approach and reinforce **prevention approaches** with more home care and field work;
- Check what types of **services and housing arrangements available**, make a mapping and assess them;
- In the financial planning, the core should come from the **national budget** (not EU funding) in order to ensure sustainability;
- Adopt a holistic approach;
- Adopt accessibility standards;
- **Involve CSOs and different stakeholders**, as well as international monitoring bodies in the monitoring of the process;
- Carry out **awareness-raising activities** towards the communities;
- Adopt national **minimum standards** to avoid inequality at local/regional level. These standards should be valid also in private institutions;
- Enhance the **coordination** across level and at the regional level;
- Elaborate clear criteria for **data** and agree on **definitions** that are comparable to other countries (use same terminology);
- **Prevent re-institutionalisation**.

3. What measures should be taken by Civil society to move away from institutional care to independent living and community-based care?

- **CSOs are key actors** in communities and are best placed to understand/implement community-based services, drive **social innovation** and elaborate sustainable community-based solutions. However in many Member States, CSOs lack of space in political and economic procedures;
- Promote **communication** between NGOs, the **coordination, cooperation and exchange** of best practices and information; Build partnerships, write/co-produce projects (identification of possible partners);
- Overcome silos and help different target groups to find a **common ground** through a common understanding of DI;
- **Map** programmes and services available to avoid duplicating work;
- Provide services and **support families**;
- Promote and communicate a **vision**; Carry out **awareness raising** on DI and focus on empowerment and on the removal of stigma. Focus also on communities who might at first resist implementation of community-based services;
- Organise **capacity-building** activities (on access to funding, proposal writing, how to develop CSOs, quality standards);
- Get in touch with users at **grassroots level** and with people with experiences of life in institutions and give them a voice and support self-advocacy groups;
- **Cooperate with policymakers** in order to identify and highlight issues and realities that they do know and promote a **bottom-up approach** to drive policy and funding changes;
- **Signal misuses of funds** and advocate for blocking funding when EFSI is not aligned with a right-based approach (watchdog role);
- **Monitor institutions** and provide **alternative reporting** and comparing evidence and established facts and figures;
- Develop **quality standards;**

- Support and phrase the **cost-effectiveness of independent living** in more economic terms in order to support a change.

Annex II: Working Group 2 - Collaborating transnationally to design community-based services to support independent living.

Project idea	Target group	Stakeholders involved	Hot to implement it?	Partners
Transition to adulthood for care-leavers (Avoid re-institutionalisation)	Young adults (16 – 18 years old) with no families, leaving institutions.	The community, institutions, public authorities (City halls, municipalities), psychologists, social housing, employment, education, activity groups.	1. Institutions for care-leavers; 2. Research of needs; 3. Training commitment; 4. Develop training material; 5. Training/monitoring/youth exchange/research; 6. Evaluation from stakeholders. (3 years)	France, Portugal, Greece, Bulgaria (good practice), research centres, independent living organisations, education organisations, job organisations, child protection organisations, policy makers.
Peer-based exchange	People with disabilities, institutionalised -> homeless	DPOs	1. Create knowledge: measurement, practices (Database); 2. Axis on finance; 3. Redirect money; 4. Disability not seen as a stigma; 5. Campaign on national and EU levels; 6. Joint action: change approach of NGOs -> partners; 7. Give money to people with disabilities to advocate for themselves. 8. Activities to "train the trainers"; 9. Knowledge management.	
Supporting care-leavers to live independently	Care leavers (17 – 21 or older)	Young people (care leavers), educators, local/regional/national authorities, civil society, service	<u>Challenges:</u> - Already working in different regions of a country is difficult; - Funding a similar project, with a good balance of partners;	NGOs, Networks of care-leavers.

		providers, family members (if possible)	- Language/communication; - Access funding for study visits and mutual learning; - Different systems, approaches, levels of development. <u>Project elements:</u> - Training; - Peer support among care-leavers; - Financial support; - Mentoring; - Involvement in community activities; - Housing; - Professional orientation (work/study).	
Mapping of projects, best practice exchange, capacity building, developing quality standards, building model-solution approach.	Children at risk, vulnerable/marginalised groups in need of support services	Civil society, EU level, National level, target groups, private sector, community at large.	1. Mapping of all services, projects and best practices involving all stakeholders; 2. Develop quality standards involving all stakeholders; 3. Based on quality standards develop and implement capacity-building for all stakeholders; 4. Develop national and EU policy recommendations; 5. Start advocacy campaign and continuous lobbying work. Develop a sustainability Roadmap. Government/EU/Private funding.	Main civil society players, umbrella organisations, national and EU governments, FICE Europe, International and national sections.
Using Erasmus + for exchanges related to independent living	Persons with disabilities	- Bodies in charge of housing and other services (social and health)	1. Training for people with disabilities (co-production approach) to train people in relevant public sectors, to deliver 'co-production approaches'; 2. Involvement of ¾ countries.	- Programme countries; - DPOs; - Civil society actors.

		- Civil society organisations		
Network of experts involved at national level	Mixed target group: service providers, Civil society organisations (disability, homeless, children), academics, national regional authorities	Mixed	Setting a forum & governance - Work programme: criteria for good DI practices; - Setting an online tool for exchange; - Submission of best practices (mapping) o Identify regions with worse/better services. o System of rating for practices. - Advice/support line for national/local authorities; - Support design/ implementation/ monitoring of national DI plans/strategy.	National authorities, government, NHRIs, Quality bodies, European institutions (delegations in the countries), MEPs.
Common standards for independent living	People with disabilities and 'relatives'	ENIL and other national NGOs + administration	- Needs assessment - Collecting good practices - UNCRPD – General comments - Dissemination (training) and lobbying	Administrations
Development of a module on community-based care and organise exchanges and analyses	- Mainly users and their families (in a larger sense) - Students/researchers	- Policymakers at all levels, including the local ones - Curriculum-makers	- To include in every curriculum for professional carers a module on community-based care and to take out from other courses elements contrary to it. - To organise exchanges and in-depth analyses on the spot: verify whether terms mean the same and build a common language - Timeline: two years	Universities, Ministries of Education, Ministries of Social Affairs.
Exchange of practitioners between regions of different countries to learn how to	Practitioners (caregivers, social workers) and management.	- People in care; - Representatives of local and regional decision makers; - Civil society (watchdog);	Close cooperation for implementation of change, following exchange visits, organisational development.	

address fears and reticence		- Civil society (experts, service providers).		


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