FRA EUROPEAN UNION AGENCY FOR FUNDAMENTAL RIGHTS

From institutions to community living

Part II: Funding and budgeting

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Contents

Introduction

"Recognizing the right to live in the community is about enabling people to live their lives to their fullest within society […]. It is a foundational platform for all other rights: a precondition for anyone to enjoy all their human rights is that they are within and among the community."

Council of Europe Commissioner for Human Rights (2012), The right of persons with disabilities to live independently and be included in the community, Issue Paper, p. 5

Article 19 of the United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD) sets out the right to live independently and be included in the community. It lies at the heart of the CRPD. Article 19 represents "the sum of the various parts of the convention" and brings together the principles of equality, autonomy and inclusion.[1] These underpin the convention's human rights-based approach to disability. This paper shortens the name of the right to the right to independent living.

Article 19 of the CRPD sets out a positive vision of "living in the community, with choices equal to others". The convention, by contrasting this with "isolation or segregation from the community", breaks down "full inclusion and participation in the community" of persons with disabilities into three elements:

- **choice:** having the opportunity to choose one's place of residence and where and with whom to live, on an equal basis with others. This includes choice of the way any support is provided;

- **support:** having access to a range of services, including personal assistance, to support living and inclusion in the community. This support should respect the individual autonomy of persons with disabilities and promote their ability to effectively take part and be included in society;

- **availability of community services and facilities:** ensuring that existing public services are inclusive of persons with disabilities.[2]

The CRPD itself does not specifically mention deinstitutionalisation. However, the Committee on the Rights of Persons with Disabilities (CRPD Committee) has underlined that it is an essential component of fulfilling the right to independent living, given that "respect[ing] the rights of persons with disabilities under article 19 means that States parties need to phase out institutionalization".[3]

There is no internationally accepted definition of deinstitutionalisation. The UN Office of the High Commissioner for Human Rights (OHCHR) has described it as "a process that provides for a shift in living arrangements for persons with disabilities, from institutional and other segregating settings to a system enabling social participation where services are provided in the community according to individual will and preference."[4] Services provided in the community – or community-based services – include personal assistance, housing adaptations, technical aids and assistive devices, peer support and counselling, and help with household tasks, among other things.[5] This report uses 'transition

from institutional to community-based support' interchangeably with 'deinstitutionalisation'.

Transitioning from institutional to community-based support has major implications for how support services for persons with disabilities are budgeted for and funded. Deinstitutionalisation can affect not only levels of funding, but also how budgets are designed and how funding is disbursed to providers and users of services. This represents a particular challenge during times of prolonged financial and economic crisis, when austerity measures can reduce the funds available for services for persons with disabilities.

From institutions to community living: FRA's reports on Article 19 of the CRPD

This report is one of a series of three reports looking at different aspects of deinstitutionalisation and independent living for persons with disabilities. They complement FRA's human rights indicators on Article 19 of the CRPD by highlighting cross-cutting issues emerging from the data that FRA collected and analysed:

- **Part I: commitments and structures:** the first report highlights the obligations the EU and its Member States have committed to fulfil.
- **Part II: funding and budgeting:** this second report looks at how funding and budgeting structures can work to turn these commitments into reality.
- **Part III: outcomes for persons with disabilities:** the third report completes the series by focusing on the impact these commitments and funds are having on the independence and inclusion persons with disabilities experience in their daily lives.

Both the European Union (EU) and its Member States are separate contracting parties to the CRPD. As each has responsibilities in the fields covered by the convention, it is a 'mixed' agreement in the context of the EU. EU law obliges Member States to implement the convention to the extent that its provisions fall within the EU's competence. When the EU accepted the CRPD, it identified independent living and social inclusion as an area of EU competence.[6]

Why this report?

This report aims to encourage more effective financing of deinstitutionalisation by highlighting challenges and successes in current approaches. It does so by bringing together some of the key issues emerging from the EU Agency for Fundamental Rights' (FRA) human rights indicators on funding and budgeting for the transition from institutional to community-based support. In particular, it looks at:

- international guidance on how to finance deinstitutionalisation;
- the role of EU funding in supporting deinstitutionalisation processes;
- how financing for deinstitutionalisation is organised at the national level.

Taken together, the analysis of these three issues gives an overview of the available financial instruments that will implement deinstitutionalisation in the EU Member States.[7]

Putting suitable funding and budgeting structures in place is just one element of achieving deinstitutionalisation. For a fuller picture of the current situation of deinstitutionalisation in the EU, this report can be read alongside FRA's human rights indicators on Article 19 of the CRPD.[8] These broadly correspond to the three main elements of the OHCHR indicator framework, which is based on three clusters:

(1) structural indicators focusing on the state's acceptance and commitment to specific human rights obligations;

(2) process indicators on the state's efforts to transform commitments into desired results;

(3) outcome indicators measuring the results of these commitments and efforts on individuals' human rights situation.

This report also goes with the two complementary reports in this series (see box).

For more information on other elements of FRA's project on the right to live independently and be included in the community, see the Annex.

Key findings and FRA opinions

The opinions outlined below build on the following key findings:

- A fundamental shift in how services for persons with disabilities are funded is needed to realise the right to independent living for persons with disabilities in practice. This includes redirecting investment from institutions to personalised services in the community that persons with disabilities guide and control.

- European Structural and Investment Funds (ESIF) play an important role in supporting deinstitutionalisation in many EU Member States. Some funding has, however, previously been spent on renovating existing institutions or building new institutions.

- For the 2014–2020 funding period, the EU has introduced measures to ensure that ESIF support deinstitutionalisation, in particular conditions that must be fulfilled before funds can be spent (so-called *ex-ante* conditionalities). Civil society has a crucial role to play in formal and informal monitoring of the use of the funds to ensure that these measures are applied in practice.

- Various levels and sectors of government share responsibility for funding deinstitutionalisation and community-based services. The involvement of a complex mix of public authorities, sources of funding and types of service providers can result in regional disparities in service provision within Member States.

- Many Member States continue to invest considerable resources in institutions for persons with disabilities. This does not promote the goal of independent living under Article 19 of the CRPD.

- Where deinstitutionalisation strategies are in place and accompanied by specific budget allocations, they can be a basis for targeted funding for the transition from institutional to community-based support.

- There is a lack of robust, comparable and timely data on budget allocations for services for persons with disabilities within individual Member States and across the EU. This impedes evidence-based policymaking and undermines efforts to achieve deinstitutionalisation.

All but one of the EU Member States, and the EU itself, have ratified the CRPD, committing themselves to achieving independent living for persons with disabilities. Realising this goal requires redirecting funding from institutional services to community-based services. Evidence that FRA has collected indicates that there is a lack of comprehensive data on whether or not such a funding shift is under way in the EU Member States. However, examples indicate that many

Member States continue to invest heavily in institutions for persons with disabilities.

FRA opinion 1

EU Member States, and the European Commission when ESIF are involved, should phase out investment in institutions. Instead, they should sufficiently fund services in the community that persons with disabilities guide and control. They should pay particular attention to developing personalised funding options such as direct payments and personal budgets.

When funding deinstitutionalisation processes, the EU Member States and the European Commission should ensure a smooth transition. They should not withdraw institutional services providing essential support before community-based services are in place.

The EU and its Member States are obliged to ensure that ESIF are used to further the implementation of the CRPD. This includes deinstitutionalisation and the right to independent living. This report shows that measures introduced for the 2014–2020 funding period can serve as powerful tools to ensure that funds are allocated in line with the CRPD and the Charter of Fundamental Rights of the EU. These measures include the *ex-ante* conditionalities and practical guidance on how to use ESIF to further deinstitutionalisation.

FRA evidence also shows, however, that realising the promise of these tools requires strengthening the monitoring of ESIF use and applying financial corrections where funds are misspent. The report follows Guideline VII of the European Ombudsman 2015 decision in highlighting the important role that public authorities and independent bodies, including civil society, can play in providing the information necessary for effective monitoring and control of ESIF.

FRA opinion 2

The European Commission should continue to work with EU Member States to set up and sustain effective, well-funded and independent ESIF monitoring committees. These committees should include representatives of disabled persons' organisations, with equal decision-making rights.

FRA opinion 3

The European Commission should apply financial corrections as stipulated by the ESIF regulations for any irregularities. This includes when funds are used to keep people with disabilities in institutional settings by renovating existing institutions or building new institutions. When imposing economic penalties, the European Commission should ensure that these steps do not worsen the fundamental rights situation of persons with disabilities.

FRA opinion 4

When monitoring and evaluating ESIF use, EU institutions and Member States should use relevant information and data that EU and national authorities, national human rights bodies and civil society organisations have collected. The European Commission should consider launching an online platform for organisations to report abuses of funds and submit complaints and shadow reports, as the European Ombudsman recommended.

Deinstitutionalisation in the spirit of the CRPD involves transforming support services for persons with disabilities, so that a range of individualised support in the community is available. This has major implications for the funding of such services.

Arrangements for funding services for persons with disabilities in the EU Member States are very complex. They often involve multiple levels of government and different funding sources, as well as a variety of service providers. Local and regional authorities play a key role within this complex picture, FRA evidence shows. Regardless of the national approach to funding community-based services, achieving deinstitutionalisation requires coordination between national, regional and local authorities, both within and across different sectors.

FRA opinion 5

EU Member States should develop mechanisms to ensure effective coordination between national, regional and local budgetary authorities involved in funding services for persons with disabilities, both within and across different sectors. This should include creating platforms for regular and structured exchanges of experiences across all bodies responsible for funding deinstitutionalisation and community-based services.

FRA opinion 6

EU Member States, and the European Commission when ESIF are involved, should develop training programmes on the implications of the CRPD for financing services for persons with disabilities. These can build on existing training for European Commission desk officers and national managing authorities on using ESIF for deinstitutionalisation. Particular attention should focus on enhancing the capacity of local and regional authorities.

The European Commission and EU Member States should ensure that persons with disabilities and their representative organisations, and national human rights bodies, are actively involved throughout the design, delivery and evaluation of training programmes.

This report underlines the lack of robust, comparable and timely data on funding for deinstitutionalisation and community-based services. Such data gaps impede needs-based budgetary planning. They also restrict the ability of Member States to make the transition from institutional to community-based support a reality.

Moreover, as FRA evidence shows, data gaps prevent Member States from showing meaningful progress in implementing Article 19 of the CRPD.

FRA opinion 7

EU Member States should collect and collate reliable, comparable and timely data on funding for deinstitutionalisation and community-based services. To improve accountability and transparency, these data should be publicly available. This could include collecting and publishing data for applying human rights-based indicators, such as those that FRA developed on Article 19 of the CRPD.

1 Funding deinstitutionalisation in compliance with the CRPD

To achieve deinstitutionalisation and comply with Article 19 of the CRPD, States Parties must make systematic changes to the types of services available to persons with disabilities. This includes replacing institutional 'one size fits all' services with personalised, user-controlled support in the community. This can extend beyond shifting funding from institutional to community-based services. It can also involve introducing 'direct payments' or 'personal budgets' to persons with disabilities, which they can use "to hire the support they require."[9] Such changes have significant consequences for financial planning and allocation.

The CRPD Committee has given further guidance on what transforming funding to support deinstitutionalisation and independent living means in practice. In its assessments of how much progress EU Member States have made in implementing Article 19 of the CRPD, it highlights the need to:

- allocate sufficient resources for deinstitutionalisation, including by adequately financing deinstitutionalisation strategies;
- reduce investment in institutions and ensuring sufficient funding for the development of community-based services, including redirecting funding from institutional services to community-based services;
- ensure adequate investment in personal assistance;
- allocate sufficient funding to support families of children with disabilities and prevent the institutionalisation of children.

However, the complexity of the challenge gives rise to a number of other considerations. A particular source of concern at the national level is that the transition from institutional to community-based services will require additional resources over both the short and long term. The OHCHR has indicated that 'double funding', to finance both institutional and community-based services simultaneously, is necessary during the transition process.[10] This allows community-based services to be built up and be in place before institutional services that provide essential support are withdrawn.

In the longer run, however, community-based services can be more cost-effective, studies suggest.[11] This is particularly the case when taking into account other factors, such as the quality of services and improved outcomes, both for persons with disabilities and for their family members. For example, cost-effectiveness – taking into account costs and outcomes – improves when services are provided in the community, an EU-funded study published in 2010 found.[12] Direct comparisons of relative costs are difficult given the range of aspects to take into account. However, the OHCHR has also underlined the importance of factoring in "the long-term impact of deinstitutionalization, including the fiscal implications of a higher number of persons with disabilities being part of the workforce and household income".[13]

"Costs often serve as an excuse for maintaining the status quo."

Council of Europe Commissioner for Human Rights (2012), The right of persons with disabilities to live independently and be included in the community, Issue Paper, p. 32

Moreover, limited budgets for social services raise difficult questions about how to prioritise funding. The CRPD Committee offers some guidance in its General Comment on Article 19. It emphasises that the right to choose where and with whom to live, as set out in Article 19 (a) of the CRPD, applies immediately. This is reflected in the importance given to factoring deinstitutionalisation into funding decisions. "States parties must take deliberate and immediate steps to reallocate funding" to realise the possibility for persons with disabilities to live independently in the community, the committee states.[14]

In contrast, the rights to access individualised support services, and community services and facilities, established under Article 19 (b) and (c), are subject to so-called 'progressive realisation'. Nevertheless, this "entails a presumption against retrogressive measures".[15] States Parties which seek to introduce retrogressive measures "in response to economic or financial crisis" are "obliged to demonstrate that such measures are temporary, necessary and non-discriminatory" and respect the core obligations of Article 19.[16]

"States should refrain from using austerity measures impacting on the provision of support [for persons with disabilities], as well as from investing in services within segregated institutions or in guardianship arrangements."

Catalina Devandas-Aguilar, Special Rapporteur on the rights of persons with disabilities, For people with disabilities, it's not about care, but about support, Press release, 3 March 2017

One of these core elements is ensuring "non-retrogression in achieving Article 19" unless these actions "have been duly justified and in accordance with international law".[17] The CRPD Committee's inquiry into how austerity-driven welfare reforms in the **United Kingdom** affect persons with disabilities gives an indication of what this means in practice. Giving its reasons for concluding that the reforms amounted to 'grave or systematic violations of the rights of persons with disabilities', the committee highlighted that "several measures have disproportionately and adversely affected the rights of persons with disabilities" and that some measures "have had a discriminatory effect on persons with disabilities".[18] The committee also noted that the "deinstitutionalization process in the [United Kingdom] has been adversely affected".[19]

2 Using European structural and investment funds to promote deinstitutionalisation

ESIF are the EU's main financial instruments for investing in job creation and a sustainable and healthy European economy and environment.[20] They account for over half of the EU budget and they run for seven years at a time. For many Member States they are a key source of funding, in addition to national resources, to achieve the transition from institutional to community-based support for persons with disabilities.

Since the EU ratified the CRPD, it has particular obligations to ensure that ESIF are used to further the implementation of the convention.[21] The Council decision accepting the CRPD specifically mentions the European Social Fund (ESF) and European Regional Development Fund (ERDF) as areas involving EU competence.[22]

The European Commission and the Member States manage ESIF jointly, but the European Commission "has the responsibility to ensure that the Member States' operational programmes comply with EU law, including EU legislation and the CRPD".[23] The ESIF cycle requires EU Member States to enter into partnership agreements with the European Commission. The European Commission then assesses and agrees on specific operational programmes proposed by the Member States.[24] Managing authorities in each Member State are responsible for the "efficient management and implementation of an operational programme".[25]

ESIF 2007–2013: Challenges in funding deinstitutionalisation

The 2007–2013 funding period witnessed major developments in the potential of the funds to address disability issues. Firstly, provisions on non-discrimination and inclusion of persons with disabilities were added to the regulations governing ESIF.[26] Secondly, a European Commission-funded study highlighted the potential of ESIF to promote deinstitutionalisation in 2009. The study pointed out that "the ESF can provide funding for the training (and re-training) of staff while the ERDF can simultaneously be used for developing social infrastructure which will support the new community-based services."[27] Thirdly, the European Disability Strategy 2010–2020 included a commitment to "promote the transition from institutional to community-based care by using [ESIF] to support the development of community-based services".[28] Nevertheless, experiences during the 2007–2013 funding period highlighted the potential fundamental rights risks of using ESIF to finance services for persons with disabilities.

Comprehensive data on what proportion of ESIF is spent on activities related to deinstitutionalisation and independent living are not available. Nevertheless, in at least 12 EU Member States – **Bulgaria**, **Czech Republic**, **Estonia**, **Greece**, **Hungary**, **Latvia**, **Lithuania**, **Poland**, **Portugal**, **Romania**, **Slovakia** and **Slovenia –** ESIF funded projects related to living arrangements for persons with disabilities during the 2007–2013 funding period, according to evidence that FRA collected for this report. In a number of cases, this included reconstructing or renovating existing institutions. This raised questions about the compatibility of this spending with the EU's and Member States' obligations under the CRPD.

A few examples highlight the different types of initiatives funded. By the end of 2013, **Romania** had spent € 41 million on reconstructing and renovating large institutions for people with disabilities, an evaluation of the allocation of 2007-2013 funds found.[29] **Slovakia** allocated € 209 million of ESIF to 136 projects in September 2010, a similar study reported. Nearly half of this amount – € 99 million – went to 47 projects building new large-scale social welfare institutions for persons with disabilities.[30]

Information provided to FRA by the **Bulgarian** Ministry of Regional Development and Public works indicates that ERDF supplied BGN 15 million (around € 8 million) for the reconstruction, renovation and equipment of institutions for children and adults. This money was provided under the project 'Support for a Suitable and Educational, Social and Cultural Infrastructure, Contributing to the Development of Sustainable Urban Areas'. As a result, 21 buildings were renovated, and 14 wheelchair ramps, 10 platforms and seven lifts were installed.[31]

Civil society has an important role in scrutinising ESIF use. For example, a **Latvian** organisation reported that, during the 2007–2013 financing period, ERDF funds totalling € 8 million were invested in five projects involving the renovation of institutions.[32] Civil society organisations raised similar concerns with regard to funding in the **Czech Republic**, **Hungary** and **Lithuania**.[33]

Such evidence prompted widespread criticism from both civil society and international human rights bodies. The criticism focused especially on harmonising the use of ESIF with the EU's obligations as a party to the CRPD since 2010. The CRPD Committee registered its concern that "in different Member States [ESIF] continue being used for maintenance of residential institutions rather than for development of support services for persons with disabilities in local communities."[34] Recommendations to several Member States further reflect this issue.[35] For example, the committee recommended that **Lithuania** "immediately refrain from using [ESIF] to renovate, maintain or construct residential institutions for persons with disabilities".[36] Civil society organisations, meanwhile, highlighted weaknesses in ESIF's monitoring and control mechanisms, and that there were no data to properly assess how the funds were used in the context of deinstitutionalisation.[37]

At the EU level, the European Ombudsman launched an own-initiative inquiry into the extent to which fundamental rights are respected in the implementation of EU cohesion policy. It was partly spurred by complaints regarding the use of ESIF in the context of deinstitutionalisation. The inquiry closed with several guidelines for improvement to ensure that the EU does not "allow itself to finance, with EU money, actions which are not in line with the highest values of the Union".[38] Although focused on ensuring compliance with the Charter of Fundamental Rights of the EU, the findings and recommendations are also relevant to the CRPD, as discussed below.

ESIF 2014–2020: Building in safeguards to avoid mistakes of the past

Such scrutiny contributed to the introduction of new measures in the regulations that govern the 2014–2020 funding period. They aim to ensure that ESIF funding complies with the EU's fundamental rights obligations. Chief among these are the *ex-ante* conditionalities, as discussed in FRA's report on commitments and structures for achieving deinstitutionalisation.[39] These preconditions ensure that "institutional and strategic policy arrangements are in place for effective investment," and must be fulfilled before funds can be disbursed.[40] Two thematic conditionalities concerning labour market inclusion and health specifically mention "measures for the shift from institutional to community-based care".[41]

Strong guidance on ESIF use reinforces these legal safeguards. The European Commission has underlined that the ERDF "should as a basic principle not be used for building new residential institutions or the renovation and modernisation of existing ones".[42] Targeted investments into institutional services are justified "in exceptional cases" to address "urgent and life-threatening risks to residents linked to poor material conditions [...], but only as transitional measures within the context of a de-institutionalisation strategy".[43]

The European Commission and individual Member States agreed on documents on funding priorities for 2014–2020. These give an insight into how the new safeguards are reflected in practice. The European Commission identified a need for measures for the shift from institutional to community-based 'care' in 12 EU Member States: **Bulgaria**, **Croatia**, **the Czech Republic**, **Estonia**, **Greece**, **Hungary**, **Latvia**, **Lithuania**, **Poland**, **Romania**, **Slovakia** and **Slovenia**.[44] Unsurprisingly, these mirror the countries where specific goals and activities to support the transition from institutional to community-based 'care' are set out in the European Commission position papers on partnership agreements and operational programmes.[45] They are also the Member States where relevant projects were funded by ESIF during 2007–2013. One exception was Croatia, which was not an EU Member State at that point.

Operational programmes do not include the level of detail required to identify the exact allocation and distribution of funds to support the transition from institutional to community-based support, FRA analysis indicates. Nevertheless, they show that there are considerable financial resources for relevant activities.

Concerning ESF, in **Bulgaria**, for example, the operational programme on Human Resources Development allocates € 336 million (ESF € 286 million; national contribution € 50 million) for the priority 'Reducing poverty and promoting social inclusion'.[46] The same operational programme in **Slovakia** includes € 369 million (ESF € 295 million; national contribution € 74 million) for the priority 'Social inclusion'.[47] Both priorities call for investments in "enhancing access to affordable, sustainable and high-quality services, including health care and social services of general interest".[48] None of the operational programmes that FRA analysed, however, provide a breakdown of the amounts to be allocated to the specific objectives falling under the relevant priorities.

More specifically, the equivalent operational programme in **Hungary** will fund capital investments to replace institutions with community-based 'care'. Although specific budget allocations are not available, the proposed outcome

indicator indicates the potential scale of the budget. Of the existing institutional places, 25 % will be replaced by community-based settings by the end of the 2014–2020 period (from a baseline of 0.5 % in 2014).[49] Other measures will support mentoring and (re-)training of professionals and of support staff working in the newly set up community-based services.

Looking beyond operational programmes, national policy documents can provide further details on budgets attached to specific ESIF-funded activities. For example, the **Latvian** document *Guidelines on the development of social services 2014–2020* provides a detailed list of measures and corresponding ESIF funding to support the transition process. Numerous activities relate to deinstitutionalisation. These range from developing individual support plans for 700 clients of state-funded institutions (total € 11 million, of which 85 % is from ESF) to funding home adaptations and other infrastructure for 1,400 persons (total € 20 million, of which 85 % is from the ERDF). These guidelines also highlight the range of possible ESIF-financed activities. They incorporate technical oversight of the implementation of deinstitutionalisation plans (€ 51,223, of which 85 % is from ESF) and research on the efficiency and sustainability of social services (€ 170,745, of which 85 % is from ESF).[50]

Many individual calls for ESIF-funded projects are still to be published. Analysis of these is beyond the scope of this report. Such research would allow a comprehensive overview of ESIF allocated to measures supporting the transition from institutional to community-based support. Still, the size of the funds gives a sense of their potential to promote deinstitutionalisation and independent living, when appropriately targeted.[51] A total of € 83 billion is allocated to ESF for 2014–2020, rising to € 120 billion when national contributions are taken into account. Of this, at least 20 % will target social inclusion, including support for the transition from institutional to community-based support. In practice, Member States have exceeded this minimum allocation, with 25.6 % of the ESIF budget allocated to social inclusion.[52] No such specific allocation is set aside for the € 196 billion of the ERDF (€ 277 billion with national contributions included). However, the European Commission has indicated that "the EUR 4.5 billion ERDF investments planned in social infrastructure will include support targeting community-based social services for vulnerable groups (disabled, children, elderly, mental health patients)."[53]

Guidance and monitoring of ESIF use: tools for realising the funds' promise

"The Committee recommends that the European Union develop an approach to guide and foster deinstitutionalization and to strengthen the monitoring of the use of the European Structural and Investment Funds so as to ensure that they are used strictly for the development of support services for persons with disabilities in local communities and not for the redevelopment or expansion of institutions. The Committee also recommends that the European Union suspend, withdraw and recover payments if the obligation to respect fundamental rights is breached."

United Nations (UN), Committee on the Rights of Persons with Disabilities (2015), Concluding observations on the initial report of the European Union, CRPD/C/EU/CO/1, 2 October 2015, para. 50

The size and complexity of ESIF mean that practical tools and control mechanisms play an important role in keeping the funds consistent with the EU's fundamental rights commitments. The three aspects that the CRPD Committee raised in its recommendations to the EU on Article 19 of the CRPD give a sense of how the EU and the Member States can ensure ESIF are used to promote deinstitutionalisation:

- guidance on using ESIF to further deinstitutionalisation;
- strengthen the monitoring of ESIF use;
- recovery of funds spent counter to the principles in the ESIF regulations.

Involving persons with disabilities through disabled persons' organisations (DPOs) is a cross-cutting obligation of the CRPD and is a key element of each aspect. However, this is not specifically mentioned in the CRPD Committee's recommendations on Article 19.

FRA Activity

Training ESIF-managing authorities on fundamental rights compliance

FRA is developing an awareness-raising training for Member State authorities responsible for implementing ESIF on respect of the Charter of Fundamental Rights in EU cohesion policy. This follows a request by the European Commission Directorate-General for Justice and Consumers.

The training builds on the European Commission's *Guidance on ensuring the respect for the Charter of Fundamental Rights of the European Union when implementing the European Structural and Investment Funds*. It aims to raise awareness of fundamental rights and their relevance in the management, monitoring and evaluation of ESIF at the national, regional and local levels.

For more information, see: *Guidance on ensuring the respect for the Charter of Fundamental Rights of the European Union when implementing the European Structural and Investment Funds*

Developing guidelines can be a strong signal of commitment to translating policy priorities into practice. The European Commission has developed two sets of guidance relating to deinstitutionalisation. This is in line with its responsibility for ensuring that ESIF operational programmes comply with EU law, including the CRPD. The first provides general advice on applying the *ex-ante* conditionalities, including those related to deinstitutionalisation.[54] The second, more specific, guidance focuses on how to 'operationalise' deinstitutionalisation through the funds.[55] It identifies examples of measures to be funded by the ESF and ERDF, such as developing deinstitutionalisation strategies and adapting infrastructure to provide community-based services.

Complementing this 'official' guidance, the European Network for Independent Living, a DPO, proposed a series of questions to assist in the evaluation of ESIF operational programmes.[56] Furthermore, a group of civil society organisations

developed a toolkit on the use of ESIF for deinstitutionalisation, which was endorsed by the European Commission (see box).

Common European guidelines on the transition from institutional to community-based care

A group of civil society organisations works together as the European Expert Group on the Transition from Institutional to Community-based Care (EEG). In 2012, it developed guidelines on how to achieve sustainable deinstitutionalisation for children, persons with disabilities and older persons. Drawing on best practice, they provide practical guidance for all public authorities involved in deinstitutionalisation on the essential elements of a successful transition process.

A *Toolkit on the use of European Union funds for the transition from institutional to community-based care* complements the main guidelines. It targets public authorities involved in the programming and implementation of ESIF, and aims to explain how they can support the development of community-based alternatives to institutional care.

For more information, see: www.deinstitutionalisationguide.eu

Turning to monitoring, the regulations governing ESIF require Member States to put in place extensive evaluation and control mechanisms to oversee use of the funds. These include a certification body, an auditing body and a monitoring committee for each operational protocol.[57] The effectiveness of these bodies has a significant impact on ensuring that the funds promote deinstitutionalisation.[58] As analysing these control measures in depth is beyond the scope of this report, it is sufficient to look briefly at the monitoring committees. They play a particular role given their pluralistic membership; they must include representatives of civil society, including "non-governmental organisations, and bodies responsible for promoting social inclusion [and] non-discrimination".[59] Monitoring committees review the implementation of each operational programme and can recommend revisions.[60]

The inclusion of 'social partners' ensures that a wider range of stakeholders take part in ESIF monitoring. Nevertheless, merely including these different actors is unlikely to be sufficient. To be effective, monitoring structures should include independent actors, as FRA evidence consistently highlights. Moreover, all members should benefit from equal decision-making rights, including voting rights.[61] Furthermore, monitoring bodies need sufficient resources and expertise to carry out their functions. This includes access to relevant information.[62]

As a last resort, the European Commission can apply financial corrections, or interrupt or suspend ESIF payments, when management and control systems do not reach the required standards.[63] It has "committed to suspending or withdrawing payments" if operational programmes do not comply with EU law, including the CRPD.[64] The European Ombudsman's guidelines for improvement also point to the need for the European Commission to "initiat[e] infringement proceedings against a Member State if its actions in the framework of the cohesion policy amount to a violation of EU law, including the Charter [of fundamental rights of the EU]".[65]

Both EU institutions and civil society organisations can play a role in providing the information that could prompt corrective measures. A case in point is the fact-finding mission to Slovakia by the European Parliament in September 2016, which highlighted delays in implementing ESIF-funded deinstitutionalisation projects.[66] The visit involved meetings with representatives of civil society and was part of a broader study on the use of ESIF for deinstitutionalisation.[67]

Community living for Europe – Structural Funds Watch

A group of civil society organisations have come together to set up an independent initiative monitoring the use of ESIF in the transition from institutional 'care' to community-based living for children, persons with disabilities and older persons. It aims to raise awareness of the potential of ESIF to support the transition from institutional 'care' to community-based living and support services by building knowledge of the regulations and mechanics of the funds and by collecting information on innovative uses of the funds in this area.

Among its first activities, it has developed briefing notes explaining the functioning of the funds. It also prepared country profiles on those Member States that use ESIF for deinstitutionalisation. FRA is an observer on the initiative's steering committee, which guides and informs its work.

For more information, see the group's website.

From the civil society side, an independent initiative is tracking how the EU and the Member States are achieving the ESIF commitment to support community living (see box). It allows individuals and organisations to submit information "on if and how the ESIF are being used on projects that develop and aid the transition to community based living".[68] This follows up, in part, the European Ombudsman's recommendation that the European Commission launch an online platform where organisations "could report abuses of funds and submit complaints and shadow reports".[69]

Many of the 2014–2020 ESIF-funded projects are still in their early stages, and the European Commission has not yet suspended or withdrawn any payments related to deinstitutionalisation. Taking such measures if compelling evidence emerges about ESIF investments in institutions would be a strong signal of the EU's commitment to ensuring that ESIF funds are used only to further deinstitutionalisation. In imposing any such economic penalties, however, the European Commission would need to ensure that they avoid "aggravat[ing] [the] situation" of "victims of fundamental rights violations".[70]

3 Financing deinstitutionalisation at the national level

ESIF provide crucial additional funding for deinstitutionalisation in almost half of EU Member States. Even where they use ESIF funds, however, responsibility for providing community-based services for persons with disabilities rests with Member States. It therefore involves considerable national resources.

FRA collected data about two crucial elements of funding at the national level: (1) how EU Member States organise funding for deinstitutionalisation and independent living; and (2) how much money is available from national budgets for community-based services. Such services are essential to both deinstitutionalisation processes and long-term independent living.[71]

Organising funding for deinstitutionalisation

"De-institutionalization […] requires a systematic transformation which includes the closure of institutions […] along with the establishment of a range of individualized support services. […] States parties must take deliberate and immediate steps to reallocate funding into realising the possibility of persons with disabilities [to live] independently in the community."

CRPD Committee (2017), General Comment No. 5 – Article 19: Living independently and being included in the community, CRPD/C/18/1, 29 August 2017, paras. 58 and 59

Understanding how funding for community-based services is organised gives an insight into how the transition process will be financed. It also indicates what changes may be necessary to realise the right to independent living. The picture in the EU is very complex, however. Various different levels and sectors of government are involved, as FRA evidence, including its summary overview of types of institutional and community-based services, shows.[72] Looking at three elements gives a sense of the diverse situation in the EU:

- responsibility for allocating budget to community-based services;
- sources of funding for community-based services;
- outsourcing of services for persons with disabilities.

Whose responsibility it is to decide on budgeting for community-based services generally depends on the national approach to administering these services.[73] In some Member States, regional governments are responsible for deciding budgets for community-based services. This is typically the case in those with federal or devolved systems. For example, in **Belgium**, the three regional governments – covering Wallonia, Flanders and the Brussels Region – allocate budget to the respective regional agencies for people with disabilities.[74] In others, usually unitary states or smaller countries such as **Estonia**, **Ireland** and **Cyprus**, decisions are mostly made at the national level.

In a third group of Member States, funding decisions involve both national and regional authorities. This often depends on the type of service. In **France**, for

instance, local authorities are generally responsible for funding decisions. However, certain activities fall under the jurisdiction of regional health agencies and national authorities.[75] In **Italy**, municipalities and the national health service jointly meet the costs of residential and semi-residential facilities for people with high support needs. In contrast, social assistance programmes are funded solely from municipal budgets.[76]

Promising practice

Coordinating budgeting across different sectors

It is important to coordinate actions across national, regional and local authorities, both within and across different sectors, as the FRA report on commitments and structures for achieving deinstitutionalisation highlights. The same is true for budgeting.

One of the pillars of **Swedish** disability policy is the principle of responsibility and financing (*Ansvarsoch finansieringsprincipen*).[77] This calls for each sector of the public administration – for example, health, housing, and accessibility of the built environment – to take responsibility for operating and financing their services in a way that is accessible to all persons, including persons with disabilities. This principle is often known as mainstreaming in other contexts.

All sectors of the public administration are therefore responsible for allocating budget for independent living in a way that ensures equal participation of people with disabilities in the community.

For more on the principle of responsibility and financing (Ansvars- och finansieringsprincipen), see the 1999 national action plan on disability policy (Från patient till medborgare en nationell handlingsplan för handikappolitiken, Proposition 1999/2000:79). See also the Socialstyrelsen website.

In addition, in a number of Member States, funding for deinstitutionalisation draws heavily on ESIF. Such Member States include **Bulgaria**, the **Czech Republic**, **Greece**, **Hungary** and **Slovakia**. In these cases, services are typically financed and administered at the regional level according to priorities and objectives that the government and the European Commission agree at the national level.

A similarly mixed picture emerges when looking at the sources of funding for community-based services. Often they involve different public authorities and multiple sources of funding. In **Slovakia**, for example, social services may be financed by a combination of contributions from the municipality or a self-governing region, payments by beneficiaries, donations, social welfare allowances administered by labour offices and specific grants from the Ministry of Labour.[78]

Similarly, funding for outpatient nursing care in **Germany** comes from a variety of sources. These include central government, statutory health insurance, social nursing care insurance, statutory accident insurance and the employer.[79] In **Hungary**, the national government provides a flat-rate annual subsidy for each user of day care services. Local authorities can supplement this with additional funding.[80] This can lead to disparities between regions and different types of service providers, as independent providers may not have access to additional local authority funding (see 'Available funding for deinstitutionalisation').

Other, non-governmental, actors can also provide funding. In **Croatia**, for example, the Open Society Mental Health Initiative has financially supported the process of deinstitutionalisation since 1997, before Croatia joined the EU. It continues to supplement EU and national funding.[81] The civil society organisation Lumos funds projects related to deinstitutionalisation in **Bulgaria**, the **Czech Republic** and **Greece**.[82] It focuses specifically on closing institutions for children, including children with disabilities.

The growing trend towards outsourcing services for persons with disabilities to non-state bodies is another budgetary factor influencing service provision. All Member States allow the provision of services to be outsourced to organisations other than public authorities, FRA evidence shows. There is, however, considerable variety in what type of non-state organisations can provide such services, and in how much service provision is outsourced. This can affect the way services are planned and budgeted for. It can also can have consequences for service quality as well as monitoring of non-state-provided services by both state and independent bodies.[83]

Some Member States allow outsourcing only to registered and licensed non-profit providers. Examples include **Ireland**, **Hungary**[84] and the **Netherlands**, as well as certain **Austrian** provinces.[85] In the **Netherlands**, for example, recognised non-profit organisations provide all services under the 2015 Social Support Act and the Long-Term Care Act.[86] Private social solidarity institutions (IPSS) run services for persons with disabilities in **Portugal**. Most of these non-profit agencies were set up by groups of families of persons with disabilities or by persons with disabilities themselves.[87]

Other Member States do not legally stipulate that outsourced services must be provided by non-profit bodies. However, this is typically what happens in practice. In **Italy**, for instance, non-profit organisations, mainly social cooperatives (*cooperative sociali*), manage and deliver most community-based services.[88]

While regulations in a third group of Member States allow services to be outsourced to a range of actors, this rarely happens in practice. These Member States include **Bulgaria**,[89] **Slovakia**[90] and **Romania**. This could be because they lack well-developed non-profit organisations that could provide community-based services, or because conditions are not favourable to private sector providers. A **Romanian** non-governmental organisation (NGO) reported that local authorities were reluctant to contract out services as the lack of a clear procedure meant that they feared losing financial or administrative control over the services.[91]

In several Member States, outsourcing to private companies is the typical model of service provision, even though non-profits are legally able to provide services.

Nearly three quarters (73 %) of care homes for older persons and persons with disabilities in the **United Kingdom** belong to the private or commercial sector. The voluntary sector runs 14 % and local authorities own 11 %. Some care homes are run by owner managers; others are part of national or international chains and have shareholders; and still others are run as charities.[92] Similarly, in **Sweden**, private companies often take part in public procurement processes to provide social services. This includes community-based services for people with disabilities.[93] Municipal and county councils decide which services to outsource.

The variety of different actors and levels of government involved in funding services for persons with disabilities creates a number of risks. For example, the UN Special Rapporteur on the rights of persons with disabilities expressed concern about the impact of decentralising the provision of support. She drew on national evidence on rights-based support for persons with disabilities and highlighted that, "where responsibility for the provision of support has been delegated to regional or local authorities, support is often underfunded and fragmented".[94] This can result in "regional disparities and inequitable access within the country" (see 'Available funding for community-based services').[95]

However, decentralising funding decisions can allow them to reflect local needs and specificities more effectively. If the different actors and levels of government coordinate better at all stages of the budgetary process, service provision is less likely to be fragmented. Ensuring the most effective use of available funds is also likely to require dedicated capacity building so that regional authorities are aware of their commitments under the CRPD.

Available funding for deinstitutionalisation

"States parties should ensure that public or private funds are not spent on maintaining, renovating, establishing [or] building existing and new institutions [or on] any form of institutionalization. […] [States parties should] allocate resources into the development of appropriate and sufficient person directed/'user'-led and self-managed support services for all persons with disabilities."

CRPD Committee (2017), General Comment No. 5 – Article 19: Living independently and being included in the community, CRPD/C/18/1, 29 August 2017, paras. 59 and 98 (k)

Looking at funding allocated to deinstitutionalisation and community-based services provides concrete evidence of Member States' commitment to the transition from institutional to community-based support. Signs of increased funding for community-based services would, for example, suggest a firm commitment to realising deinstitutionalisation, especially if coupled with reduced spending on institutional services. Similarly, a shift in funding towards more individualised services such as personal assistance or personal budgets would indicate a move towards more user-led services. This would reflect the requirements of Article 19.

FRA's human rights indicators on Article 19 of the CRPD look at different aspects of funding to ensure independent living. These include budget allocated for providing community-based services, including specific support services; budget for moving from institutional settings to living arrangements of an individual's

choice; and budget for organisations supporting persons with disabilities to develop independent living skills. They also aim to track changes in budget allocation over time. FRA also looked separately at budgets for providing physical adjustments and assistive devices to enable independent living.[96] However, most of these indicators cannot currently be applied because of a lack of comparable, up-to-date and reliable data on many of these elements (see 'The need for more and better data').

Where data are available, they paint a mixed picture of budgetary steps towards realising deinstitutionalisation. Five important elements of the funding situation emerge from FRA's analysis:

- balance between funding for institutional and community-based services;
- regional disparities in budget allocation within Member States;
- funding associated with deinstitutionalisation strategies;
- changes in budget allocation over time;
- sustainability of funding over time.

Significant funds continue to be invested in institutional services across the EU, FRA's data suggest. This investment may come at the expense of funding for community-based services. In Flanders in **Belgium**, for example, data from 2013 indicate that € 992 million went to residential services for persons with disabilities. In comparison, about € 120 million was allocated to services including family-type housing, assisted housing and support in the family in 2013.[97] Similarly, around half of the 2014 budget of the Walloon Agency for Disability went to residential care for children and adults. As a result, living in institutions was the main option available to persons with disabilities in the region.[98]

A similar picture emerges in **Germany**. Residential facilities received € 11.4 billion, 83 % of total net expenditure for integration assistance services for people with disabilities, 2012 data show. In comparison, € 2.3 billion (17 %) went to community-based services.[99] In the **Czech Republic**, institutional care represents 85 % of all residential services for persons with disabilities, says a report on services for persons with disabilities.[100] It argues that most money for social services also goes to institutional care.[101]

There are regional disparities in funding for community-based services in many Member States. Although other socio-economic and demographic factors account for some of this discrepancy, it may also reflect the decentralisation of responsibility for providing of services to regional or local authorities. In **Denmark**, for example, budgets for home care services, personal assistance and food services varied from € 13 million to € 134 million in municipalities with similar populations in 2015.[102] Similarly, in **Italy**, per capita expenditure on 'interventions and social services' for persons with disabilities ranged from € 303 in Valle d'Aosta to € 17,326 in South Tyrol in 2011.[103] In the **United Kingdom**, local authorities spent between £ 350 and £ 640 per capita per year on adult social care in 2012–2013, a report by the National Audit Office found. Adults with learning disabilities (intellectual disabilities) typically had the most

expensive packages of care. It concluded that, where differences cannot be explained by local area characteristics, local policy choices or different levels of efficiency may explain the variation.[104]

More positively, deinstitutionalisation strategies can be a basis for targeted funding for the transition from institutional to community-based support.[105] The government resolution setting out **Finland's** deinstitutionalisation strategy also allocated € 30 million a year from 2010 to 2015 for investment assistance for housing projects for persons with disabilities, and up to € 5 million a year to provide and build assisted housing, for example.[106]

In several other cases, funding for strategies largely stems from ESIF. This underlines the importance of EU funds for achieving deinstitutionalisation. The **Lithuanian** action plan for the transition from institutional care to community-based services for people with disabilities and orphans comes with a budget of € 22 million from ESIF and € 8 million of national government funding.[107]

The FRA indicators also aim to assess changes in budget allocations for community-based services over time. Although gaps in the data prevent firm conclusions, available evidence suggests a mixed picture. Personal assistance is the one specific form of support mentioned in Article 19 of the CRPD. A look at budgets available for it gives a sense of the complexity of this issue.[108] In **Latvia**, for example, funding for accompanying assistance services (*asistenta pakalpojums*) increased more than threefold between 2010 and 2015, doubling between 2013 and 2014 alone. Still, it remains less than 10 % of the cost of group homes.[109]

In **Sweden**, personal assistance is much longer established. There, spending on the state-funded comprehensive personal assistance scheme for individuals with higher support needs has been steadier. Expenditure rose from € 2.1 billion in 2010 to € 2.5 billion in 2012, and then stayed at the same level in 2013 and 2014.[110] Data from **Austria** underline the difficulty of getting an overall picture of the funding situation in federal states. In the federal state of Upper Austria, funding for personal assistance fluctuated between 2013 and 2015: € 6.8 million in 2013, € 7.7 million in 2014 and € 7.4 million in 2015. However, no data for specific services are available for the federal state of Vienna.[111]

International human rights actors have highlighted the impact of austerity measures in some Member States on the provision of services enabling independent living. Following his 2013 visit to **Spain**, the Commissioner for Human Rights of the Council of Europe raised concerns about substantial budgetary cuts in the disability sector. These had consequences for the availability and accessibility of community-based services. He highlighted that "the lack of access to support services is especially problematic for persons who have been deinstitutionalised."[112] For its part, the CRPD Committee found that reductions in housing benefits in the **United Kingdom** have "curtailed the right of persons with disabilities to choose a place of residence in accordance with Article 19 of the Convention", while "social care packages have been reduced in the context of further budgetary constraints at the local level".[113]

These fluctuations in budgets raise questions about the sustainability of certain services. This can be particularly significant when community-based services or deinstitutionalisation measures are funded on a project basis rather than as part

of a systematic redesign of service provision. Where funding is attached to a deinstitutionalisation strategy, one risk is that funding ceases when the strategy ends. Another danger is delays to specific projects. In **Cyprus** in 2014, for example, the Council of Ministers approved funding for a project aiming to deinstitutionalise eight persons with intellectual disabilities from the state psychiatric hospital. The finance was supposed to be available by 2015.[114] On account of "unforeseen circumstances", however, the project did not commence.[115] Concerns regarding sustainability of ESIF-funded projects are discussed in the FRA report *From institutions to community living: commitments and structures for achieving deinstitutionalisation.*[116]

4 Need for more and better data

"Data and information should be disaggregated systematically (art. 31) by disability across all sectors including with respect to housing, living arrangements, social protection schemes as well as access to independent living and support and services. The information should allow for regular analyses on how de-institutionalization and transition to support services in the community have progressed."

CRPD Committee (2017), General Comment No. 5 – Article 19: Living independently and being included in the community, CRPD/C/18/1, 29 August 2017, para. 96

There are significant gaps in the data available on funding and budgeting for community-based services.[117] This makes it difficult to get the solid overview of the funding picture within and across EU Member States that evidence-based policy making requires. It also means that many of the FRA human rights indicators cannot currently be applied. Most importantly, the absence of robust data could also indicate a lack of focus on realising deinstitutionalisation.

Looking at three of these issues in turn highlights areas that policy actors need to address to improve data availability, as Article 31 of the CRPD requires:

- lack of clearly identifiable budget for community-based services for persons with disabilities;
- no national collation of data;
- different data sources and data collection methodologies.

If community-based services for persons with disabilities are a clearly identifiable budget item, it helps show that funding is shifting from institutional to community-based support. Such transparency can also facilitate coordination between different levels and sectors of government. However, this component is not generally visible in state or regional budgets, according to evidence that FRA has collected.

In some cases, this is because there is no distinction between institutional services and community-based services for persons with disabilities: both types of service appear jointly under the social security or welfare sections of the budget. In **Spain**, for example, none of the autonomous communities' budgets show community-based services as an item. It is therefore not possible to identify the allocated budget.[118] There is, however, evidence that this is changing in a number of Member States as more community-based services emerge. For instance, **Slovenia** recently introduced the term "community-based services" as a budgetary item.[119]

The way data are collected and presented in other Member States means that it is not possible to identify which part of the budget for social services covers services for persons with disabilities. This is often because data are collected by type of service, rather than by users of the service. In **Latvia**, for example, the Ministry of Welfare publishes the data on the basis of information from the local governments. The available data indicate budgets allocated to specific

community-based services. However, different groups of persons may use them, not just persons with disabilities.[120]

Similarly, data are available for various types of services in **Poland**, but do not distinguish groups of service users. Only specialised care services for persons with 'mental disabilities' are clearly identifiable as being for persons with disabilities. This service comes from the state budget, so it appears separately in the statistical reports on social assistance that the Ministry of Labour and Social Policy prepares.[121]

Two examples show different options for providing more specific budgetary information. The **Danish** statistical office provides comprehensive information on national, regional and municipal budgets for all specific services provided for in the Act on Social Services.[122] In **Germany**, the ministry of finance of each federal state (*Land*) is responsible for issuing yearly budget plans. These plans detail the budget allocated annually for various types of community-based services.[123]

A second issue concerns gaps in national collation of data. This happens particularly in Member States where financing for community-based services is organised on a regional level (see 'Organising funding for deinstitutionalisation'). In **Italy**, **Slovakia** and **Finland**, for example, details on the allocation of budgets for community-based services are often not systematically compiled at the regional level, information provided to FRA indicates. This makes it difficult to collate and analyse information nationally.

In the **United Kingdom**, each local authority or devolved government is free to plan its own budget according to its own priorities. This includes the amount it allocates to community-based social support services. Differences across regions in spending per person on services for younger adults with physical and learning (intellectual) disabilities cannot be fully explained because of a lack of relevant data, according to a report by the National Audit Office.[124]

Finally, potential sources of information on budgets and financing for community-based services are very diverse, as FRA's efforts to identify relevant data highlight. Ranging from one-off academic reports to annual statistical compendiums, these resources vary enormously in their scope, level of detail and methodology. There are also issues with timeliness, as annual data are often published only several years later. This has a significant impact on the comparability of the data available, both within and between countries. Furthermore, the data that are available are often incomplete, as the FRA overview of types of institutional and community-based services reveals. They may, for example, cover only certain forms of community-based service, some sources of funding or particular administrative regions.

One approach is to collect and present data through national statistical offices. **Austria**'s statistical office collects and analyses data on budget allocations for community-based services annually. The country's federal governance structure means, however, that details are not publicly available for all federal states.[125] The **Finnish** statistical office publishes raw data on spending by municipalities on its website, allowing further analysis.[126] In **Germany**, on the other hand, it is the Federal Health Monitoring Information System that publishes data on the allocation of budget to community-support services. The published data are based on administrative data.[127]

In other Member States, including **Belgium**,[128] **Cyprus**,[129] **Latvia**,[130] **Poland**[131] and the **United Kingdom**,[132] some of the data used in this report came from annual reports published by the ministry responsible for services for persons with disabilities. Notably, parts of the data sought in the context of the FRA indicators on Article 19 of the CRPD are not publicly available in many Member States. Instead, they were provided to FRA by different, mostly public, authorities after specific requests from FRA in-country researchers.[133]

Conclusions

Deinstitutionalisation cannot happen without significant changes in the way services for persons with disabilities are budgeted for and financed. The wide range of different public authorities, sectors and service providers involved in funding services for persons with disabilities makes this a major challenge for EU Member States. However, it means that progress in altering funding towards deinstitutionalisation and community-based services is a strong signal of concrete steps towards fulfilling the promise of the convention.

"The cost of deinstitutionalization should be addressed by a reallocation of resources, which may require targeted investments, particularly in the initial phase, effective partnerships and prioritization. Adequate resources need to be available to build the new support infrastructure – both accessible mainstream community services and specific support services – prior to altering the balance of service provision. Funding opportunities should be directed to sustaining systemic reforms."

United Nations General Assembly (2014), Thematic study on the right of persons with disabilities to live independently and be included in the community, A/HRC/28/37, 12 December 2014, para. 27

The data and analysis in this report reveal certain key issues for Member States to consider in their ongoing deinstitutionalisation processes. Without a shift in the way services are funded, the gap between the promise of Article 19 and the reality that persons with disabilities experience is likely to remain.

Annex:
FRA's project on the right to live independently and be included in the community

FRA is mandated to provide assistance and expertise to EU institutions and Member States when they implement EU law and policy.[134] This includes EU action to implement the CRPD, which the EU accepted in 2010. FRA has provided evidence and expertise concerning implementation of the CRPD in a number of key areas, including political participation,[135] legal capacity,[136] involuntary placement and treatment,[137] independent living,[138] non-discrimination,[139] and violence against children with disabilities.[140]

In this context, FRA started work in 2014 on a project exploring how the 28 EU Member States are fulfilling the right to independent living. It specifically focuses on deinstitutionalisation. This project incorporates three interrelated activities:

- Mapping what types of institutional and community-based services for persons with disabilities are available in the 28 EU Member States. This mapping provides EU and national policy actors with baseline information to help them to identify where to focus their efforts to promote the transition from institutional to community-based support. A summary overview of this mapping was published in October 2017.[141]
- Developing and applying human rights indicators to help assess progress in fulfilling Article 19 of the CRPD and to highlight gaps in current provision and availability of data in the 28 EU Member States.[142] These indicators were also published in October 2017.[143]
- Conducting fieldwork research in select EU Member States (Bulgaria, Finland, Ireland, Italy and Slovakia) at different stages of the deinstitutionalisation process to gain a better understanding of the drivers of and barriers to the transition from institutional to community-based support. The findings of this in-depth research will come out in 2018.

This report examines the evidence gathered under the second activity: developing and applying human rights indicators on the right to independent living.

Developing and applying human rights indicators

The FRA indicator-related work is based on the framework for human rights indicators that the OHCHR developed.[144] FRA first used this model for the CRPD in 2014, when it developed and applied human rights indicators on Article 29 of the CRPD on the right to participate in political and public life.[145]

The FRA project on the right to independent living of persons with disabilities broadly corresponds to the three main elements of the OHCHR indicator framework. This framework is based on three clusters of indicators: (1) structural indicators focusing on the State's acceptance and commitment to specific human rights obligations; (2) process indicators on the State's efforts to transform commitments into desired results; and (3) outcome indicators measuring the results of these commitments and efforts on individuals' human rights situation.

The three papers stemming from the FRA indicators on Article 19 of the CRPD reflect this approach. The first paper in the series focuses on structural commitments to achieving deinstitutionalisation, the present paper focuses on financing and highlights Member States' budgetary efforts to implement these commitments, and the third paper assesses the situation on the ground.

Endnotes

[1] Office of the High Commissioner for Human Rights Regional Office for Europe (2012), *Getting a life – living independently and being included in the community*, p. 24.

[2] These three components are analysed in greater depth in: Council of Europe Commissioner for Human Rights (2012), *The right of people with disabilities to live independently and be included in the community*, Strasbourg, Council of Europe; and United Nations General Assembly (2014), *Thematic study on the right of persons with disabilities to live independently and be included in the community*, A/HRC/28/37, 12 December 2014.

[3] See, in particular, CRPD Committee (2017), General Comment No. 5 – Article 19: Living independently and being included in the community, CRPD/C/18/1, 29 August 2017, para. 49. Many organisations, including FRA, submitted written comments on the draft.

[4] United Nations General Assembly (2014), *Thematic study on the right of persons with disabilities to live independently and be included in the community: report of the Office of the United Nations High Commissioner for Human Rights*, A/HRC/28/37, 12 December 2014, para. 25.

[5] See: European Expert Group on the transition from institutional to community-based care (2012), *Common European Guidelines on the transition from institutional to community-based care*, chapter 4; and CRPD Committee (2017), General Comment No. 5 – Article 19: Living independently and being included in the community, CRPD/C/18/1, 29 August 2017.

[6] See: Council Decision of 26 November 2009 concerning the conclusion, by the European Community, of the United Nations Convention on the Rights of Persons with Disabilities, OJ L 23, 27 January 2010, Appendix.

[7] A great deal has been written about funding community-based services more widely. See, for example, UN Special Rapporteur on the Rights of Persons with Disabilities (2017), *Report on access to rights-based support services for persons with disabilities*.

[8] See FRA's webpage on the Article 19 indicators.

[9] UN Human Rights Council (2016), *Report of the Special Rapporteur on the rights of persons with disabilities*, A/HRC/34/58, 20 December 2016, para. 62.

[10] United Nations General Assembly (2014), *Thematic study on the right of persons with disabilities to live independently and be included in the community: report of the Office of the United Nations High Commissioner for Human Rights*, A/HRC/28/37, 12 December 2014.

[11] See, for example, Conroy, J. W. (2004), *The Costs of Supporting People with Developmental Disabilities in Institutional*

Versus Community Settings, Center for Outcome Analysis, cited in: Council of Europe Commissioner for Human Rights (2012), *The right of persons with disabilities to live independently and be included in the community*, Issue Paper.

[12] Mansell, J., Knapp, M., Beadle-Brown, J. and Beecham, J. (2007), *Deinstitutionalisation and community living – outcomes and costs: report of a European Study. Volume 1: Executive Summary,* Canterbury: Tizard Centre, University of Kent.

[13] United Nations General Assembly (2014), *Thematic study on the right of persons with disabilities to live independently and be included in the community: report of the Office of the United Nations High Commissioner for Human Rights*, A/HRC/28/37, 12 December 2014, para. 27.

[14] CRPD Committee (2017), General Comment No. 5 – Article 19: Living independently and being included in the community, CRPD/C/18/1, 29 August 2017, para. 59.

[15] CRPD Committee (2017), General Comment No. 5 – Article 19: Living independently and being included in the community, CRPD/C/18/1, 29 August 2017, para. 44.

[16] *Ibid*., para. 43. See also Committee on Economic, Social and Cultural Rights, General Comment No. 3, para. 10.

[17] CRPD Committee (2017), General Comment No. 5 – Article 19: Living independently and being included in the community, CRPD/C/18/1, 29 August 2017, para. 38 (f).

[18] CRPD Committee (2016), *Inquiry concerning the United Kingdom of Great Britain and Northern Ireland carried out by the Committee under Article 6 of the Optional Protocol to the Convention: report of the Committee*, CRPD/C/15/R.2/Rev.1, para. 113.

[19] CRPD Committee (2016), *Inquiry concerning the United Kingdom of Great Britain and Northern Ireland carried out by the Committee under Article 6 of the Optional Protocol to the Convention: report of the Committee*, CRPD/C/15/R.2/Rev.1, para. 96.

[20] See the Commission's webpage on ESIF. A glossary of terminology related to ESIF is also available on a Commission webpage.

[21] A detailed analysis of the use of ESIF in the context of deinstitutionalisation and independent living is available in: Office of the High Commissioner for Human Rights Regional Office for Europe (2012), *Getting a life – living independently and being included in the community*; Open Society Foundations (2012), *The European Union and the right to independent living: structural funds and the European Union's obligations under the Convention on the Rights of Persons with Disabilities*, New York, Open Society Foundations; Open Society Foundations (2015), *Community not confinement: the role of the European Union in promoting and protecting the right of people with disabilities to live in the community*, New York, Open Society Foundations; European Parliament (2016), *European Structural and Investment Funds and people with disabilities in the European Union*, Policy department C: citizens' rights and constitutional affairs.

[22] See: Council Decision of 26 November 2009 concerning the conclusion, by the European Community, of the United Nations Convention on the Rights of Persons with Disabilities, OJ L 23, 27 January 2010, Appendix.

[23] European Commission (2014), *Report on the implementation of the UN Convention on the Rights of Persons with Disabilities by the European Union*, SWD (2014) 182 final, Brussels, 5 June 2014, para. 99.

[24] For more information, see Chapter 1 of FRA (2015) *Fundamental rights: challenges and achievements in 2014. FRA annual report*, Luxembourg, Publications Office.

[25] See the Commission's webpage on the issue.

[26] European Commission (2009), *Ensuring accessibility and non-discrimination of people with disabilities: toolkit for using EU Structural and Cohesion Funds*.

[27] European Commission (2009), *Report of the Ad-hoc expert group on the transition from institutional to community-based care*, p. 21.

[28] European Commission (2010), *European Disability Strategy 2010-2020: A renewed commitment to a barrier-free Europe*, COM(2010) 636 final, Brussels, 15 November 2010, p. 6.

[29] Romanian Institute for Public Policy (*Institutul pentru Politici Publice*) (2013), *The outcomes of structural funds investment during the current financial exercise – the lesson we (failed to) learn for 2014 - 2020*, October 2013.

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The transition from institution- to community-based support for persons with disabilities is a complex process that requires multifaceted efforts. These include putting in place commitments and structures for achieving deinstitutionalisation and measuring outcomes for persons with disabilities. This report shows that effectively funding the deinstitutionalisation process is a vital element. Bridging the gap between the promise of Article 19 and the reality that persons with disabilities experience likely requires a shift in the way services are funded. A great deal of knowledge and experience in each of these areas is being gathered across EU Member States. This report and the two other reports in FRA's three-part series dedicated to this topic provide important insights that can support ongoing processes of change.