

From institutions to community living

Part I: Commitments and structures

**Europe Direct is a service to help you find answers to
your questions about the European Union**

Freephone number (*):
00 800 6 7 8 9 10 11

Photo (cover & inside): © AdobeStock (from left to right: Dan Race; Rawpixel.com; Dörr&Frommherz)

More information on the European Union is available on the internet (<http://europa.eu>).

Luxembourg: Publications Office of the European Union, 2017

FRA – print:	ISBN 978-92-9491-768-3	doi:10.2811/322544	TK-01-17-811-EN-C
FRA – web:	ISBN 978-92-9491-767-6	doi:10.2811/64917	TK-01-17-811-EN-N

© European Union Agency for Fundamental Rights, 2017

Reproduction is authorised provided the source is acknowledged. For any use or reproduction of photos contained herein, permission must be sought directly from the copyright holder.

Printed on elemental chlorine-free bleached paper (ECF)

Contents

Introduction	4
Key findings and FRA opinions	6
1 Commitment to deinstitutionalisation	9
Convention on the Rights of Persons with Disabilities: setting standards for action	9
European Structural and Investment Funds: committing to promote deinstitutionalisation	11
National commitments: guiding deinstitutionalisation in Member States	13
2 Turning commitment into reality	19
Conclusions	24
Annex:	
FRA's project on the right to live independently and be included in the community	25
Developing and applying human rights indicators	26

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 convention. It 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.

The CRPD 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 Article 19, given that "independent living and being included in the community refer to life settings outside residential institutions of all kinds".²

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."³ This report uses 'the transition from institutional to community-based support' interchangeably with 'deinstitutionalisation'.

Achieving this transition is therefore not limited to changing the place or type of residence. Instead, it entails a profound shift from environments characterised by routine and an 'institutional culture' to those where persons with disabilities exercise choice and control over their lives and any support they may require. As such, 'deinstitutionalisation' implies not merely closing institutions. It encompasses developing a "range of services in the community [...] to prevent the need for institutional care."⁴

Why this report?

Discussions are under way at the European Union (EU) and national levels about how best to realise the transition from institutional to community-based support. This report contributes to these by bringing together some of the key issues that have emerged from the EU Agency for Fundamental Rights' (FRA) human rights indicators on Member States' political and practical commitment to deinstitutionalisation. In particular, it looks at:

- commitment to deinstitutionalisation:
 - the international and EU legal and political instruments related to deinstitutionalisation that Member States have committed to implementing;
 - strategies and commitments guiding deinstitutionalisation at the national level;
- turning commitment into reality:
 - the administrative and organisational structures through which to achieve deinstitutionalisation, and coordination between them.

Together, these issues give an overview of the legal and policy framework that will implement deinstitutionalisation in the EU Member States.

Putting in place political commitments and implementation structures is just one element of achieving deinstitutionalisation. To get a fuller picture of the current situation in the EU, this report can be read alongside the FRA human rights indicators on Article 19 of the CRPD. 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).⁵

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.

From institutions to community living: FRA 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:** this first report highlights the obligations the EU and its Member States have committed to fulfil.
- **Part II: funding and budgeting:** the [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.

Key findings and FRA opinions

The FRA opinions outlined below build on the following key findings:

- By ratifying the CRPD, the EU and 27 of its Member States have committed to realising the right of persons with disabilities to live independently and be included in the community, including through deinstitutionalisation. Ireland has signed but not yet ratified the CRPD.
- The EU has strengthened its role in supporting deinstitutionalisation by requiring that the European Structural and Investment Funds (ESIF) support the transition from institutional to community-based support for persons with disabilities.
- Most EU Member States have adopted strategies that cover deinstitutionalisation. However, some strategies lack the adequate funding, clear timeframes and benchmarks, and involvement of disabled persons' organisations required to make them effective.
- Few EU Member States have expressly committed to not building new institutions or to stopping new admissions into existing institutions.
- There is wide variety in how EU Member States organise deinstitutionalisation. Responsibility for community-based services rests with national authorities in some Member States, regional authorities in others, and a mixture of regional and national authorities in a final group.
- Coordinating the different levels and sectors of government involved in deinstitutionalisation presents a major challenge. In particular, relatively few Member States have set up modes of cooperation between the different sectors involved in the process.

Realising the right of persons with disabilities to live independently and be included in the community requires implementing meaningful and sustainable deinstitutionalisation. FRA evidence shows that one crucial starting point is a

strategy on or covering deinstitutionalisation. Previous FRA opinions call for disabled persons' organisations to be closely involved in developing such policies.⁶

FRA Opinion 1

All EU Member States should adopt deinstitutionalisation strategies. These strategies should be evidence based, drawing on a comprehensive needs-based mapping of the status of deinstitutionalisation. They should also have a sufficiently broad scope to cover the different sectors involved in the transition from institutional to community-based support. These include health, employment and housing, in addition to support services for persons with disabilities.

EU Member States should ensure that they actively involve persons with disabilities and their representative organisations throughout the design, implementation and evaluation of the strategy.

FRA Opinion 2

EU Member States' deinstitutionalisation strategies should include specific targets with clear deadlines. Member States should also adequately finance the implementation of these strategies.

FRA Opinion 3

EU Member States should ensure that independent bodies regularly review the implementation of deinstitutionalisation strategies. Member States should consider developing indicators to track progress during the lifetime of the strategy to highlight implementation gaps.

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 planning and delivery of such services.

This report underlines that, regardless of the national approach to commissioning and administering community-based services, achieving deinstitutionalisation requires coordination between national, regional and local authorities, both within and across different sectors.

FRA Opinion 4

EU Member States should develop mechanisms to ensure effective coordination between relevant municipal, local, regional and national authorities. Member States should also facilitate the transfer of support services across different administrative sectors.

Deinstitutionalisation requires that the phasing out of institutional services be coupled with developing accessible support services in the community. This entails a cross-sectoral approach that integrates both specialised services for persons with disabilities and general services available to the local community as

a whole. Deinstitutionalisation is also likely to require developing new and innovative support services that are adaptable to individual needs.

FRA Opinion 5

EU Member States should develop mechanisms to ensure effective coordination between relevant sectors involved in deinstitutionalisation, including housing, employment, health and social services.

Member States, and the European Commission when ESIF are involved, should ensure that newly developed community-based support services are financially and practically sustainable.

1 Commitment to deinstitutionalisation

One of the key building blocks underpinning deinstitutionalisation is commitments by public authorities to support the transition from institutional to community-based support for persons with disabilities. In addition to signalling the political will that is crucial to achieving deinstitutionalisation, these commitments can set a blueprint for how to implement it in practice.

Convention on the Rights of Persons with Disabilities: setting standards for action

Article 19 of the CRPD is the core global standard for independent living.⁷ It breaks down the right to live, be included and participate in the community, on an equal basis with others, into three elements. Each is equally applicable to all persons with disabilities, irrespective of the type or severity of their impairment:

- **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.⁸

The right to choose where and with whom to live is immediately applicable, the CRPD Committee emphasises in its General Comment on Article 19.⁹ In contrast, the rights to access individualised support services, and community services and facilities, under Article 19 (b) and (c) are subject to so-called 'progressive realisation'. This obliges States Parties to the convention to take measures to realise these rights "to the maximum of [their] available resources".¹⁰ The CRPD Committee also highlights the close links between Article 19 and other convention rights, in particular the decision-making rights set out under Article 12 on equal recognition before the law.¹¹

As of October 2017, 27 EU Member States have formalised their commitment to fulfilling the right to live independently and be included in the community by ratifying the CRPD.¹² **Ireland** has signed but not yet ratified the convention. In addition, the EU itself accepted the CRPD in 2010. This marked the first time a regional integration organisation accepted one of the core international human rights conventions. As both the EU and its Member States are separate contracting parties, and each has responsibilities in the fields covered by the CRPD, the convention 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.¹³

As FRA evidence consistently shows, ratifying the CRPD has spurred wide-ranging legal and policy reforms concerning the right to independent living, including deinstitutionalisation.¹⁴ Most EU Member States have examples of new or amended legislation to promote choice of living arrangements, personalised support, and access to community services and facilities open to the general population.¹⁵

A few examples highlight the range of reform initiatives. Several Member States, including **Bulgaria**¹⁶ and **Latvia**,¹⁷ have introduced a statutory right to personal assistance, albeit with various degrees of scope.¹⁸ Other reforms have focused on financial support. In **Belgium**, the Flemish Parliament reformed the funding system provided by the Flemish Agency for People with a Disability. In addition to the basic budget provided to all persons with disabilities and support needs, a second, larger, personalised budget is available as either cash or a voucher for particular services.¹⁹ In 2016, the **Italian** Parliament approved a law on support measures for persons with disabilities. This included, among other goals, a dedicated annual fund to foster deinstitutionalisation and the development of community-based services.²⁰

Realising the right to independent living in practice remains, however, a significant challenge. In its General Comment on Article 19, the CRPD Committee noted "a gap between the goals and spirit of article 19 and the scope of its implementation".²¹ Six particular challenges emerge from the CRPD Committee's assessment of Member States' efforts to fulfil the obligations of Article 19. Several relate specifically to deinstitutionalisation:

- high levels of institutionalisation and, in some Member States, a trend towards reinstitutionalisation;
- lack of choice of residence for persons with disabilities because there is a shortage of alternative, community-based living arrangements;
- insufficient availability of personal assistance services;
- greater financial resources for institutional services than community-based services;
- means testing of benefits, which impedes the right to live in the community with an adequate standard of living;²²
- absence of adequately funded strategies for independent living and/or deinstitutionalisation.²³

Concrete actions to follow up the CRPD Committee's recommendations on how to address the gap between standard and reality will show how far the Member States are committed to fulfilling their CRPD obligations.

European Structural and Investment Funds: committing to promote deinstitutionalisation

The EU's own acceptance of the CRPD gives it a particular role to play beyond helping to coordinate actions to implement the convention's provisions.²⁴ Currently, the most significant example of the EU's obligations under the CRPD concerning deinstitutionalisation is ESIF.²⁵ ESIF account for over half of EU funding and are the main financial instruments through which the EU invests in job creation and a sustainable and healthy European economy and environment.²⁶ The European Commission and the Member States manage them jointly. However, the European Commission "has the responsibility to ensure that the Member States' operational programmes comply with EU law, including EU legislation and the CRPD".²⁷

Following criticism of ESIF for funding the construction of new institutions or renovation of existing institutions,²⁸ the regulation governing ESIF for 2014–2020 includes specific protections to ensure that funds are used to support deinstitutionalisation. This built on an earlier policy commitment in the European Disability Strategy 2010–2020 to "promote the transition from institutional to community-based care by using [ESIF] to support the development of community-based services".²⁹ These additions are an important signal of the EU embedding its commitment to promoting deinstitutionalisation within law and policy.

The central aspect of the commitment to promoting deinstitutionalisation in the ESIF regulation takes the form of a so-called 'ex ante conditionality', a requirement that must be met before funds can be disbursed. Linked to the objective of active inclusion, a specific condition requires Member States to show that their national policies to reduce poverty include "measures for the shift from institutional to community based care", where relevant needs have been identified.³⁰ Further guidance from the European Commission clarifies the scope of 'relevant needs' as covering those Member States where "the shift to community-based care has not yet been completed".³¹

For 2014–2020, 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.** In a further five Member States (**Denmark, Ireland, Malta, Portugal and Spain**), partnership agreements contain a commitment to deinstitutionalisation and identify measures to support the process, FRA's review of 2014–2020 partnership agreements between the European Commission and individual EU countries reveals.³² The annual country-specific recommendations prepared by the European Commission may include further measures relating to deinstitutionalisation. These aim to support EU Member States to reach their targets under the Europe 2020 strategy for smart, sustainable and inclusive growth.³³

The nature of the reference to deinstitutionalisation varies widely, however. Some partnership agreements, such as that with **Croatia**, are very detailed, list

wide-ranging measures and allocate specific budgets. Others – for example, those with **Hungary, Ireland and Romania** – take a more general approach. In a third group, including **Bulgaria** and the **Czech Republic**, there are general commitments in partnership agreements, supplemented by specific measures in the respective operational programmes.

Partnership agreements with **Greece** and **Spain** refer to deinstitutionalisation but remain vague about specific activities in support of the transition process. For example, the Greek Partnership Agreement makes an indirect reference to actions related to the transition from institutional to community-based care. It refers to the need to fulfil obligations arising from the Memorandum of Cooperation signed between the Commissioner for Employment and the Minister of Health covering 2014 and 2015. This memorandum addresses issues related to access to health services, in particular mental health services, for people with limited resources, people in remote areas, people from vulnerable groups and uninsured citizens.³⁴

The remaining 11 EU Member States do not specifically address the transition from institutional to community-based care in partnership agreements. This means that they will not use money from ESIF to support the process, rather than that no deinstitutionalisation measures are in place. The **Finnish** Partnership Agreement, for instance, makes no reference to deinstitutionalisation. However, the government has committed to ensuring that, by 2020, no persons with intellectual or developmental disabilities live in institutions.³⁵ It has also put in place a housing programme to attain this goal.³⁶

In addition, partnership agreements with most Member States identify specific concerns in relation to full participation and inclusion of people with disabilities. These concerns are linked to deinstitutionalisation in a wider sense. In addition to measures under thematic objective 9 on social inclusion, the agreements include specific actions to support objective 8 on sustainable and quality employment and objective 10 on investing in education and training.

Nevertheless, concerns about the use of ESIF in the context of deinstitutionalisation persist.³⁷ In its assessment of the EU's progress in implementing the CRPD, the CRPD Committee noted that "despite changes in regulations, [ESIF] continue to be used in different member States for the maintenance of residential institutions rather than for the development of support services for persons with disabilities in local communities."³⁸ Its recommendations call for the EU to develop "an approach to guide and foster deinstitutionalization and to strengthen the monitoring of the use of [ESIF]". It also urged the EU to "suspend, withdraw and recover payments if the obligation to respect fundamental rights is breached".³⁹ As projects under the 2014–2020 funding period are rolled out, the EU's response to this recommendation will come under particular focus.⁴⁰

National commitments: guiding deinstitutionalisation in Member States

"States parties have the immediate obligation to enter into strategic planning [...] to replace any institutionalized settings with independent living support services. The margin of appreciation of States parties is related to the programmatic implementation but not to the question of replacement."

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. 42

The EU Member States are responsible for implementing many aspects of Article 19, as they are in charge of social policy. Two particular issues give a sense of how and to what extent Member States have committed themselves to achieving deinstitutionalisation as part of their obligations under the CRPD:

- the adoption and implementation of strategies and action plans on deinstitutionalisation;
- commitments not to build new institutions for persons with disabilities.

Strategies have become crucial tools for implementing the CRPD in the decade since its adoption, FRA research shows.⁴¹ This is equally true of deinstitutionalisation. The CRPD Committee highlights the "lack of deinstitutionalization strategies and plans" as one of the remaining barriers to the implementation of the right to live independently.⁴² It has also clarified that strategies in themselves are not sufficient. Instead they must be "adequately funded", include "clear time frames and benchmarks" and be adopted "in cooperation with organisations of persons with disabilities".⁴³ The FRA indicators on Article 19 of the CRPD provide detailed information on each of these aspects of deinstitutionalisation strategies.

Evidence collected by FRA indicates that two-thirds of EU Member States have either adopted a dedicated strategy on deinstitutionalisation (six Member States) or included measures for deinstitutionalisation in a broader disability strategy (eight Member States), or both (three Member States).⁴⁴ Table 1 presents an overview of these strategies.

Table 1: Strategies on deinstitutionalisation and for persons with disabilities

EU MS	Strategy or action plan
AT	National Action Plan on Disability 2012–2020 (<i>Nationaler Aktionsplan Behinderung 2012–2020</i>)
BG	National Strategy for Equal Opportunities for Disabled People 2008–2015 (<i>Стратегия за осигуряване на равни възможности на хората с увреждания 2008 – 2015 г.</i>)
CY	First National Action Plan for Disability for the Implementation of the Convention of the Rights of Persons with Disabilities 2013–2015

CZ	National Plan for the Promotion of Equal Opportunities for Persons with Disabilities 2015–2020 (<i>Národní plán podpory rovných příležitostí pro osoby se zdravotním postižením na období 2015–2020</i>)
	Strategy of Social Inclusion 2014–2020 (<i>Strategie sociálního začleňování 2014–2020</i>)
	Action Plan for the Implementation of the National Strategy of Protection of Children's Rights, 2012–2015 (<i>Akcční plán k naplnění Národní strategie ochrany práv dětí na období 2012–2015</i>)
EE	Special Care and Welfare Development Plan for 2014–2020 (<i>Erihoolekande arengukava aastateks 2014–2020</i>)
EL	National Action Plan Psychargos C (2011–2020) (<i>Εθνικό Σχέδιο Δράσης ΨΥΧΑΡΓΩΣ Γ' 2011-2020</i>)
	National Strategic Framework for Social Integration (<i>Εθνικό Στρατηγικό Πλαίσιο για την Κοινωνική Ένταξη</i>)
FI	Housing Programme for Persons with Intellectual and Developmental Disabilities 2010–2015 (<i>Kehitysvammaisten asumisohjelma (KEHAS)</i>)
HR	Plan of Transformation and Deinstitutionalization of Social Welfare Homes and Other Legal Entities Performing Social Welfare Activities in the Republic of Croatia for the Period 2011–2016 (2018) (<i>Plan transformacije i deinstitucionalizacije domova socijalne skrbi i drugih pravnih osoba koje obavljaju djelatnost socijalne skrbi u Republici Hrvatskoj u periodu 2011. – 2016. (2018.)</i>)
	Operational Plan of Transformation and Deinstitutionalization of Social Welfare Homes and Other Legal Entities Performing Social Welfare Activities in the Republic of Croatia for the Period 2014–2016 (<i>Operativni plan deinstitucionalizacije i transformacije domova socijalne skrbi i drugih pravnih osoba koje obavljaju djelatnost socijalne skrbi u Republici Hrvatskoj 2014. – 2016.</i>)
HU	Strategy for the Substitution of Accommodation of People with Disabilities at Social Institutions 2011–2041 (<i>Stratégia a fogyatékos személyek számára ápolást-gondozást nyújtó szociális intézményi férőhelyek kiváltásáról 2011-2041</i>)
	Development Principles for the Implementation of the Strategy for the Substitution of Accommodation of People with Disabilities at Social Institutions (2011–2041), 2015–2020' (<i>Fejlesztési alapvetések a fogyatékos személyek szociális intézményi férőhelyi kiváltásáról szóló stratégia (2011-2041) végrehajtásához, 2015-2020</i>)
	National Disability Programme 2015–2025 (<i>Országos Fogyatékosügyi Program 2015–2025</i>)
	Action Plan for the Implementation of the National Disability Programme for 2015–2018 (<i>Országos Fogyatékosügyi Program végrehajtásának 2015–2018. évekre vonatkozó Intézkedési Terve</i>)
IE	Time to Move on from Congregated Settings – A Strategy for Community Inclusion
IT	Biennial Action Plan for the Promotion of the Rights and the Integration of People with Disabilities (2014–2015) (<i>Programma di azione biennale per la promozione dei diritti e l'integrazione delle persone con disabilità</i>)
LT	Action Plan for the Transition from Institutional Care to Community-Based Services for People with Disabilities and Orphans for 2014–2020 (<i>Lietuvos Respublikos socialinės apsaugos ir darbo ministro įsakymas „Dėl perėjimo nuo institucinės globos prie šeimoje ir bendruomenėje</i>

	<i>teikiamų paslaugų neįgaliesiems ir likusiems be tėvų globos vaikams 2014–2020 metų veiksmų plano patvirtinimo)</i>
LU	Reform of the Psychiatric Sector in Luxembourg and Mental Health Policy (<i>Réforme de la psychiatrie et politique de santé mentale au Luxembourg</i>)
LV	Guidelines for the Implementation of the United Nations Convention on the Rights of Persons with Disabilities 2014–2020 (<i>Apvienoto Nāciju Organizācijas Konvencijas par personu ar invaliditāti tiesībām īstenošanas pamatnostādnes 2014.–2020.gadam</i>)
	Guidelines on the Development of Social Services 2014–2020 (<i>Sociālo pakalpojumu attīstības pamatnostādnes 2014.–2020.gadam</i>)
MT	National Policy on the Rights of Persons with Disability
RO	National Strategy 'A Society without Barriers for Persons with Disabilities' 2016–2020 (<i>Planului operațional privind implementarea Strategiei naționale "O societate fără bariere pentru persoanele cu dizabilități 2016–2020</i>)
	National Strategy on Social Inclusion and Poverty Reduction 2014–2020 (<i>Strategia națională privind incluziunea socială și reducerea sărăciei 2014–2020</i>)
SK	Strategy of Deinstitutionalisation of the System of Social Services and Foster Care in the Slovak Republic (<i>Stratégia deinštitucionalizácie systému sociálnych služieb a náhradnej starostlivosti v Slovenskej republike</i>)
	National Priorities for Development of Social Services for the Period 2015–2020 (<i>Národné priority rozvoja sociálnych služieb na roky 2015–2020</i>)
	National Programme for the Development of Living Conditions of Persons with Disabilities for the Years 2014–2020 (<i>Národný program rozvoja životných podmienok osôb so zdravotným postihnutím na roky 2014–2020</i>)

Source: FRA, 2017

Setting clear targets and a timeframe for their achievement can help make strategies more effective. The strategies set out concrete targets and a timeframe for meeting them in each of the nine Member States with a dedicated deinstitutionalisation strategy and five of the 11 Member States with a disability strategy that includes deinstitutionalisation measures. Some of these targets are numerical, specifying numbers of persons to deinstitutionalise or a date for completing deinstitutionalisation. Examples include **Bulgaria**,⁴⁵ with a target concerning deinstitutionalisation of children, **Estonia**⁴⁶ and **Finland**.⁴⁷ Other targets focus on particular milestones, as in **Slovakia**.⁴⁸

Another indication of the likely effectiveness of a strategy is if it comes with a monitoring mechanism. FRA's analysis indicates that most Member States with strategies on or including deinstitutionalisation measures have set up mechanisms to monitor their implementation. These mechanisms include or engage with the frameworks set up to monitor implementation of the CRPD under Article 33 (2) of the convention in several Member States, including **Austria**, **Estonia** and **Germany**. However, the relevant strategies in **Cyprus**,

Greece, Italy, Malta and **Romania** do not include provisions for any monitoring mechanisms.

"States parties should [...] establish mechanisms to monitor [...] de-institutionalization strategies and the implementation of living independently within 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, para. 98 (m)

Where monitoring mechanisms exist, most involve disabled persons' organisations (DPOs). This is a key requirement of Article 4 (3) of the CRPD, which sets out the general obligation for parties to the CRPD to "closely consult with and actively involve persons with disabilities", through their representative organisations, in developing and implementing legislation and policies to implement the convention. For example, to monitor the implementation of the **Latvian** Guidelines on the development of social services 2014–2020, the Ministry of Welfare set up a Social Services Development Council. This includes representatives of relevant state bodies, providers of services, municipalities, DPOs and experts.⁴⁹ Where DPOs are not included, questions can arise concerning the independence and objectivity of the monitoring.

Monitoring mechanisms' activities take different forms. Some Member States, including **Bulgaria**,⁵⁰ the **Czech Republic**⁵¹ and **Slovakia**, prepare regular – typically annual – progress reports. In others, including **Austria** and **Finland**,⁵² interim reports track progress in implementing measures. The mid-term report on implementation of the **Austrian** national disability strategy included input from civil society. It indicates that 58 % of 250 measures defined in the action plan were completed or implemented by the end of 2015; another 34 % are partly implemented or in preparation.⁵³

Monitoring reports also provide an opportunity for critical reflections on what can be improved in the future. The 2016 review of the **Slovak** National Programme for the Development of Living Conditions for Citizens with Disabilities proposes amendments for the remaining period of the strategy. These include amendments with respect to support for community-based services and realisation of deinstitutionalisation.⁵⁴ The review of the **Finnish** Housing Programme for Persons with Intellectual and Developmental Disabilities 2010–2015 collected good practices and identified a number of measures for improvement in 2016–2020.⁵⁵

Express moratoriums on building new long-stay residential institutions and allowing new admissions to existing institutions are a second signal of meaningful commitment to achieving deinstitutionalisation and independent living. Both the CRPD Committee and the UN Special Rapporteur on the rights of persons with disabilities called for such moratoriums.⁵⁶ These pledges reduce the need for later deinstitutionalisation, by preventing institutionalisation in the first

place. As part of its indicators on Article 19 of the CRPD, FRA looked at both types of commitments.

"I call on [Member States] to immediately stop new placements in institutions, while at the same time adopting clear action plans for phasing out institutions and replacing them with community based services."

Council of Europe Commissioner for Human Rights, Deinstitutionalisation in the work of the Council of Europe Commissioner for Human Rights, Strasbourg, 2 October 2014

Around one third of EU Member States have committed to not building new institutions for persons with disabilities, FRA evidence indicates. This pledge is typically made either in national disability or deinstitutionalisation strategies, as in **Austria**,⁵⁷ **Finland**⁵⁸ and **Ireland**,⁵⁹ or in other ways that are not legally binding. In **Slovakia**⁶⁰ and **Sweden**,⁶¹ in contrast, it is enshrined in law.

Other Member States, including **Bulgaria**,⁶² **Estonia**, **Hungary**⁶³ and **Romania**,⁶⁴ have not explicitly committed to not building new institutions. Instead, they have set themselves goals for deinstitutionalisation that would be difficult to meet if new institutions were built. In **Estonia**, with support from the European Regional Development Fund, the proportion of people who receive 24-hour services in institutions with more than 30 service slots should be reduced to 30 % by 2020, the Special Care and Welfare Development Plan 2014–2020 states.⁶⁵

The nature of these commitments, however, varies significantly. A look at a few key features highlights the diversity of approaches:

- **Timeline:** While the responsible minister in **Romania** has committed to finalising the deinstitutionalisation process by 2020, the deadline for fulfilling the **Bulgarian** commitment is 2025, and the timeframe for institutions to close in **Hungary** is 2041.
- **Impairment group:** Several commitments relate to specific impairment groups. The **Finnish** commitment relates specifically to persons with intellectual disabilities. In contrast, the **Irish** government committed to closing "all unsuitable psychiatric settings". The CRPD Committee has called for "special attention [to] be paid to persons with psychosocial and/or intellectual disabilities" in deinstitutionalisation strategies.⁶⁶
- **Size of accommodation:** The **Austrian** commitment does not specify the maximum number of persons with disabilities who could live together in 'deinstitutionalised' accommodation. It does, however, call for replacing large institutions with smaller group homes, shared flats or single apartments. The commitment in **Hungary**, in contrast, is limited to closing institutions with more than 50 places for persons with disabilities. While emphasising that institutions can differ in size, the CRPD Committee states that smaller group homes with five to eight individuals cannot be called independent living.⁶⁷

- **Date of commitment:** Although many commitments are linked to CRPD ratification, those in **Austria** and **Sweden** stem from the 1990s. **Swedish** legislation from 1997 specified that residential institutions would not be recognised by law after December 1999.⁶⁸

In contrast, there are concerns in several Member States about a tendency towards reinstitutionalisation, as progress towards the transition to community-based support risks being undone. In **Denmark**, both DPOs and independent national human rights institutions have expressed concern about a return to large institution-like accommodation.⁶⁹ They highlight that the government has refrained from defining a legal maximum number of users of a housing unit and that housing units intended for 40–100 persons with intellectual disabilities have been built.⁷⁰ In **Hungary**, legislation effective from 2015 permits the opening or enlargement of institutions that provide ‘therapeutic care’ for persons with disabilities, psychiatric conditions or addictions. The institutions may have up to 50 places.⁷¹

A corollary of the commitment not to build institutions is stopping new admissions to existing institutional settings. Fewer Member States have made such commitments, FRA evidence suggests. The **Estonian** government has committed to not increasing the number of persons with psychosocial disabilities living in institutions.⁷² With the financial support of the European Regional Development Fund, institutions with more than 30 service slots will be reorganised to prevent institutional care. Similarly, **Greece** has a policy commitment to stop admitting persons with psychosocial disabilities to institutional care.⁷³

2 Turning commitment into reality

"De-institutionalization [...] requires a systemic transformation, which includes the closure of institutions [...] along with [the] establishment of a range of individualized support services [...] as well as inclusive community services. Therefore, a coordinated, cross-government approach which ensures reforms [...] on all levels and sectors of government, including local authorities, is required."

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. 58

The transition from institutional to community-based support requires profound reform of social services to ensure that they facilitate both individual choice and inclusion in the community. In many cases this entails a wide-ranging reorganisation of the way support services for persons with disabilities are designed and provided. FRA has collected data about four important elements of the structural shift to services that promote and enable independent living in the community:

- responsibility for setting up inclusive community-based services;
- coordinating deinstitutionalisation;
- transferability of services across different administrative areas;
- sustainability of community-based services.

Reflecting their obligations under the CRPD, all EU Member States provide a variety of community-based services for persons with disabilities. FRA's background paper gives an overview of both institutional and community-based services in place in each of the 28 EU Member States.⁷⁴ It reveals considerable divergence in the availability of such services and the extent to which they reflect the will and preferences of individual users.

This section complements that analysis by focusing on the national bodies and organisations responsible for implementing the structural reforms inherent to deinstitutionalisation processes. As with social services more broadly, the level of government at which decisions on community-based services are made can have a significant impact on what services are in place and how they are organised.⁷⁵

FRA's analysis identifies three main approaches to administering community-based services for persons with disabilities. In some countries, usually unitary states, the national government is responsible for overseeing and providing community-based services. Others, often countries with federal or devolved systems, decentralise responsibility to regional or local authorities. A further two groups of Member States have a mixed approach: in the first, the national and regional levels share responsibility; in the second, the responsible level of government depends on the type of service.

Where responsibility for community-based services lies at the national level, it typically falls under the mandate of the social ministry, or other bodies responsible for social or health policies. However, in some of these countries – for example, **Bulgaria**, **Latvia** and **Poland** – while a national body holds overall responsibility, the implementation of services is delegated to local

administrations. For example, in Bulgaria, the State Social Assistance Agency (*Агенция за социално подпомагане*) has overall responsibility for providing services, through its local Social Assistance Directorates.⁷⁶ As the deinstitutionalisation process is a national government commitment, new community-based services are devised at the national level by the Social Assistance Agency. However, municipalities decide which of these services they will actually provide, taking into account local needs.⁷⁷

Where regions are responsible for community-based services, the particular distribution is frequently based on the country's specific federal or devolved structure. For example, in **Germany**, a total of 23 local and regional social welfare agencies, which operate at the level of federal states, communal associations (*Kommunalverbände*) or city states (*Stadtstaaten*), are responsible for contracting providers of community-based services and for funding and overseeing their work.⁷⁸ Similarly, in **Spain**, the 17 Autonomous Communities (*Comunidades Autónomas*) have exclusive jurisdiction over social services.⁷⁹ In some Member States, however, the national government retains a steering role. Although the devolved administrations and local authorities have responsibility for community-based services in the **United Kingdom**, the devolved administrations are responsible for the overall direction and spending rounds.

A few examples highlight the practical challenges presented by having multiple bodies involved in the organisation and delivery of community-based services. One possible consequence is the need for various bodies at different levels of government to approve decisions. For example, in **Portugal**, a decision by a Local Committee for Social Action that a particular community-based service is required is subject to approval by the relevant District Centre of the Institute for Social Security.⁸⁰ The District Centre's Statement of Opinion about funding is in turn discussed and decided at the central level as part of the overall budget planning process. Similarly, different levels of regional government are involved in the **Czech Republic** and **Slovakia**. In Slovakia, primary responsibility for both residential and community-based services lies with the self-governing regions,⁸¹ while low-threshold day care centres for children and adults with disabilities, and respite and nursing care services are delegated to towns.⁸²

The wide range of different bodies and levels of government with responsibility for community-based services underlines the importance of coordination for effective deinstitutionalisation. This involves cooperation across two axes. Firstly, national, regional and local public authorities with overlapping or interlinked responsibilities for services need to cooperate closely ('vertical' coordination). This is particularly important in federal or decentralised Member States. However, it also requires 'horizontal' coordination between the different sectors without whose services the transition from institutional to community-based living cannot be realised. These include, among others, housing, health and employment services.

"Effective deinstitutionalization requires a systemic approach, in which the transformation of residential institutional services is only one element of a wider

change in areas such as health care, rehabilitation, support services, education and employment, as well as in the societal perception of disability.”

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

The absence of coordination can be a major barrier to the implementation of effective deinstitutionalisation. For example, it can result in uneven provision of services, so that persons with disabilities in some regions or municipalities benefit from a greater variety or higher quality of services than individuals in other areas. Moreover, it can create gaps in service provision, leaving persons with disabilities without a particular service, for example access to accessible housing or appropriate medical care. This would hinder their transition to living in the community.

Both the CRPD itself and the CRPD Committee address the question of vertical coordination between different levels of national governance structures. Article 4 (5) of the CRPD recalls that the “Convention extend[s] to all parts of federal states without any limitations or exceptions.” The CRPD Committee has expressed concerns about the implementation of this provision in its assessment of several Member States’ implementation of the convention. In its concluding observations on **Austria**, for example, the CRPD Committee raised the concern that “a federal system of government [...] has led to undue fragmentation of policy, especially as the *Länder* (regions) are the providers of social services.”⁸³ More generally, it urged **Germany** to “ensure that federal, Land and local authorities are aware of the rights set out in the Convention and of their duty to effectively ensure the implementation of those rights.”⁸⁴

Member States have addressed the issue of ensuring such vertical coordination in different ways, according to evidence that FRA has collected. Some Member States have set out vertical coordination in legal instruments. In **Slovakia**, for example, the Act on Social Services requires state bodies such as offices of labour, social affairs and family, health care providers and schools to cooperate with towns, self-governing regions and the Ministry.⁸⁵ Municipalities in **Sweden** have a legal duty to cooperate with their county council (*Landsting*), the social insurance office (*Försäkringskassan*) and the employment office (*Arbetsförmedlingen*) to effectively manage available resources.⁸⁶ In the **United Kingdom**, the Care Act 2014 requires the local authorities to ensure cooperation with relevant partners, who are, in turn, required to cooperate with the authority.⁸⁷

Other Member States highlighted the importance of vertical coordination by setting it out as policy priorities in relevant policy documents. The **Croatian** Strategy for Social Welfare Development, for instance, specifically calls for the strengthening of horizontal and vertical coordination between all stakeholders.⁸⁸ However, the country’s Disability Ombudsman, which is responsible for monitoring implementation of the CRPD under Article 33 (2) of the convention, has raised concerns that services are not effectively coordinated or monitored in

practice.⁸⁹ This can lead to discrepancies in the availability of services for persons with disabilities. For example, some services are delivered by several providers while others are non-existent in certain areas. In **Greece**, the National Strategic Framework on Social integration identifies coordination of integration policies as a policy priority for 2015–2020.⁹⁰

Others have set up dedicated coordination mechanisms. The 23 federal state agencies responsible for community-based services in **Germany**, for example, come together in a Federal Working Group of Welfare Agencies (*Bundesarbeitsgemeinschaft der überörtlichen Träger der Sozialhilfe*) responsible for representing, coordinating and advancing the integration of assistance services.

The CRPD Committee's call for coordination across "all levels and sectors of government" to achieve deinstitutionalisation is explored in greater depth by the OHCHR and the UN Special Rapporteur on the rights of persons with disabilities.⁹¹ The OHCHR highlighted the particular importance of support during the transition from institutional to community living. It emphasised that "such support should be based on effective coordination among health-care and social-service providers, and the housing sector."⁹² More generally, the Special Rapporteur called on governments to "consider establishing a comprehensive system to coordinate the effective access to support of persons with disabilities", which covers "all support needs across all sectors of society".⁹³

Nevertheless, much fewer data are available on how Member States aim to ensure horizontal coordination between different sectors of public services in implementing deinstitutionalisation. In addition to their provisions on vertical coordination mentioned above, the **Greek** and **Croatian**⁹⁴ strategies that cover deinstitutionalisation include provisions on strengthening cooperation across different sectors. For example, the Greek National Strategic Framework on Social integration includes setting up a national mechanism for the horizontal monitoring and coordination of policies.⁹⁵ Examples of more informal coordination at the practical and policy levels are likely to be more widespread.

Tied closely to coordination among and between different levels and sectors of government is the issue of transferability of services across different administrative areas. Exercising the right to choose one's place of residence and access social services on an equal basis with others requires that persons with disabilities can change their place of residence, for example by deciding to move from one town to another. The CRPD Committee addresses part of this issue in its General Comment on Article 19, expressing concern that "inappropriate" decentralisation of service provision could result in "disparities between local authorities and unequal chances of living independently within the community."⁹⁶

The transfer of services across different administrative areas is not regulated in the majority of EU Member States, according to evidence that FRA collected as part of its human rights indicators on Article 19 of the CRPD. Only around one third of Member States, including **Belgium, Croatia, Denmark, Estonia, Finland, Germany, Sweden** and the **United Kingdom**, have specific provisions. In Denmark, for example, the former municipality of residence

continues to pay for personal assistance until the new municipality decides on the individual's eligibility.⁹⁷ In **Finland**, persons with disabilities can apply for financial support from both the former and the new municipality of residence.⁹⁸ The former municipality is responsible for covering the costs of adjustments and devices in the new home if the person is not able to move until these are provided. If these adjustments and devices can be provided after the person has moved, the new municipality covers the costs.

This possibility of transferring services across administrative regions is not, however, necessarily complemented by support to complete the necessary administrative processes. There are only a few isolated examples where cooperation between municipalities to realise the possibility to transfer services is regulated in greater detail, FRA data reveal. Similarly, only in a few cases is there a legal provision that ensures support for the person concerned during the transfer process. One example is the **United Kingdom** Care Act of 2014, which includes a provision for close cooperation between the municipalities that a person is moving from and to. This cooperation ensures that the individual's needs are taken into account to the greatest possible extent.⁹⁹

Ensuring access to a range of personalised community-based services that are inherent to effective deinstitutionalisation also requires that such services are sustainable over time. This is particularly relevant to services that may operate as part of specific programmes or pilot projects. They create valuable opportunities to develop innovative types of personalised support, but may end when the programme concludes. Such uncertainty and disruption can have a tremendous impact on the lives of people with disabilities, as the preliminary findings of FRA's fieldwork research on the deinstitutionalisation process reveal.¹⁰⁰

ESIF funding periods are time-bound. That can create risks to the sustainability of services created and operating with the help of European financing. For example, where ESIF funds contribute a large proportion of a service's financing, Member States may struggle to cover the shortfall at the end of the funding period. Civil society organisations have raised concerns about the sustainability of ESIF-funded services – for example, in **Bulgaria**¹⁰¹ and **Slovakia**. In the report of its fact-finding visit to Slovakia on the use of ESIF for deinstitutionalisation, the Committee on Petitions of the European Parliament highlighted "the condition of sustainability of the deinstitutionalization projects", and called for "exact follow-up to measure the sustainability level".¹⁰²

Conclusions

Deinstitutionalisation is at the core of the change brought about by the CRPD. It requires fundamental changes in the way persons with disabilities live, and how the support they receive to do so is provided. These encapsulate the paradigm shift that the convention as a whole demands. This makes deinstitutionalisation a significant challenge for EU Member States. It means, however, that progress in implementing deinstitutionalisation and broader independent living is a strong signal of concrete steps towards fulfilling the promise of the convention.

"Th[e] transition from residential care to community living [...] is now a clear legal obligation undertaken by the Member States and by the European Union under Article 19 of the UN Convention on the Rights of Persons with Disabilities."

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. 8

The data and analysis in this report reflect the huge diversity of deinstitutionalisation efforts under way in the EU Member States. Nevertheless, a number of commonalities have emerged. This suggests that effective deinstitutionalisation strategies and coordination of the different actors involved are key issues for Member States to consider in their ongoing deinstitutionalisation processes.

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.¹⁰³ 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. These include political participation,¹⁰⁴ legal capacity,¹⁰⁵ involuntary placement and treatment,¹⁰⁶ independent living,¹⁰⁷ non-discrimination¹⁰⁸ and violence against children with disabilities.¹⁰⁹

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 2017.¹¹⁰
- 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.¹¹¹ These indicators were also published in October 2017.¹¹²
- Conducting fieldwork research in select EU Member States (Bulgaria, Finland, Ireland, Italy and Slovakia) at different stages of the deinstitutionalisation process to better understand 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.¹¹³ FRA first used this model with respect to 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.¹¹⁴

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 also reflect this approach. This paper focuses on structural commitments to achieving deinstitutionalisation, the paper on financing highlights 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 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. 16 (c). Many organisations, including FRA, submitted [written comments on the draft General Comment](#).

³ 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.

⁴ 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*, p. 27.

⁵ FRA (2017), *From institutions to community living*, Part II: funding and budgeting, and FRA (2017), *From institutions to community living*, Part III: outcomes for persons with disabilities, Luxembourg, Publications Office.

⁶ FRA (2016), *Fundamental Rights Report 2016*, Luxembourg, Publications Office.

⁷ See also: Council of Europe (1996), *European Social Charter (Revised)*, Art. 15.

⁸ 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.

⁹ 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. 39-41

¹⁰ See: UN General Assembly (2006), *Convention on the rights of persons with disabilities*, Article 4(2). More information on progressive realisation is available in: Office of the UN High Commissioner for Human Rights (2008), *Frequently asked questions on economic, social and cultural rights*, Factsheet No. 33.

¹¹ CRPD Committee (2014), *General Comment No. 1 – Article 12: Equal recognition before the law*, para. 46; 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, paras. 27 and 81; OHCHR (2014), *Thematic study on the right of persons with disabilities to live independently and be included in the community*, A/HRC/28/37, paras. 15-18. See also: FRA (2013), *Legal capacity of persons with intellectual disabilities and persons with mental health problems*, Luxembourg, Publications Office.

¹² Further information on the ratification status of the EU Member States, in addition to details of the bodies established under Article 33 of the CRPD, is available on FRA's [website](#).

¹³ 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.

¹⁴ See FRA (2015), *Implementing the UN CRPD: An overview of legal reforms in EU Member States*, FRA Annual Reports.

¹⁵ For further information, see FRA's indicators on Article 19 of the CRPD.

¹⁶ Bulgaria, Regulations for Implementation of Social Assistance Act, 1 June 2010, Article 53a.

¹⁷ Latvia, Disability Law of 20 May 2010, Section 1 (1).

¹⁸ For more information, see: European Network on Independent Living (2015), *Personal assistance services in Europe 2015* and Sainsbury, R., Lawson, A., and Priestley, M. (2017), *Social protection for disabled people in Europe: Synthesis report*, European network of academic experts in the field of disability.

¹⁹ Belgium, Flemish Decree regarding individualised funding for persons with a handicap (*Decreet houdende de persoonsvolgende financiering voor personen met een handicap en tot hervorming van de wijze van financiering van de zorg en de ondersteuning voor personen met een handicap*), 25 April 2014.

²⁰ Italy, Law No. 112 of 22 June 2016 on Support measures for persons with disabilities deprived of family support (*Disposizioni in materia di assistenza in favore delle persone con disabilità grave prive del sostegno familiare*).

²¹ 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. 15.

²² See in particular: 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.

²³ See, for example, the CRPD Committee's concluding observations on Cyprus, the Czech Republic, Denmark, Germany and Spain. All concluding observations are [available on the CRPD Committee's website](#).

²⁴ Information on ESIF concerning budgets for deinstitutionalisation is presented in the accompanying paper on funding for deinstitutionalisation processes.

²⁵ For further analysis of the relationship between ESIF and Article 19 of the CRPD, see: 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.

²⁶ See the Commission's [webpage on these funds](#).

²⁷ 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.

²⁸ See, for example: European Coalition for Community Living (ECCL) (2010), *Wasted money, wasted time, wasted lives...A wasted opportunity?* and European Parliament (2016), *European Structural and Investment Funds and people with disabilities: focus on the situation in Slovakia*, Policy department C: citizens' rights and constitutional affairs.

²⁹ 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.

³⁰ Regulation (EU) No 1303/2013 of the European Parliament and the Council of 17 December 2013 laying down common provisions on the ERDF, the ESF, the CF, the EARFD and the EMFF and laying down general provisions on the ERDF, the ESF, the CF and the EMFF and repealing Council Regulation (EC) No 1083/2006, OJ, L 347, 20.12.2013, Annex XI, p. 320. For further information on ESIF and the ex-ante conditionalities, see Chapter 1 of FRA (2015) *Fundamental rights: challenges and achievements in 2014. FRA annual report*, Luxembourg, Publications Office.

³¹ European Commission (2014), *Guidance on Ex ante Conditionalities for the European Structural and Investment Funds: Part 2*, p. 259.

³² All partnership agreements are available on the [Commission's webpage on these agreements](#).

³³ All the 2017 country-specific recommendations are available on the [Commission's webpage on the recommendations](#).

³⁴ Greece, Ministry of Development and Competitiveness (Υπουργείο Ανάπτυξης και Ανταγωνιστικότητας), *Partnerships Agreement 2014-2020 (Σύμφωνο Εταιρικής Σχέσης 2014-2020)*, May 2014, p. 103-106.

³⁵ Finland (2012), Government Resolution on securing individual housing and services for persons with intellectual disabilities (*Valtioneuvoston periaatepäätös kehitysvammaisten henkilöiden yksilöllisen asumisen ja palvelujen turvaamisesta/Statsrådets principbeslut om trygghande av individuellt boende och tjänster för personen med utvecklingsstörning*).

³⁶ Finland (2010), Housing Programme for Persons with Intellectual and Developmental Disabilities 2010-2015, (*Kehitysvammaisten asumisohjelma*).

³⁷ See, for example: European Parliament (2016), *European Structural and Investment Funds and people with disabilities in the European Union*, Policy department C: citizens' rights and

constitutional affairs; and European Network on Independent Living – European Coalition for Community Living (2016), *Working together to close the gap between rights and reality*.

³⁸ 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.

³⁹ 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. 51.

⁴⁰ In particular from initiatives such as *Community Living for Europe: Structural Funds Watch*.

⁴¹ FRA (2015), *Implementing the UN CRPD: an overview of legal reforms in EU Member States*. See also FRA's annual Fundamental Rights Reports.

⁴² 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. 15 (e).

⁴³ 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. See, for example, the Committee's concluding observations on Austria (CRPD/C/AUT/CO/1) and Hungary (CRPD/C/HUN/CO/1).

⁴⁴ Much more detailed information is available in FRA's indicators on Article 19 of the CRPD.

⁴⁵ Bulgaria, Council of Ministers (*Министерски съвет*) (2010), Action plan for the implementation of the national strategy 'Vision for the Deinstitutionalisation of Children in the Republic of Bulgaria (*План за действие за изпълнение на Националната стратегия „Визия за деинституционализация на децата в Република България*)', 24 November 2010, p. 7.

⁴⁶ Estonia, Ministry of Social Affairs (*Sotsiaalministeerium*) (2014), *Special Care and Welfare Development plan for 2014-2020* (*Erihoolekande arengukava aastateks 2014-2020*), p. 36.

⁴⁷ Finland (2012), Government Resolution on securing individual housing and services for persons with intellectual disabilities (*Valtioneuvoston periaatepäätös kehitysvammaisten henkilöiden yksilöllisen asumisen ja palvelujen turvaamisesta/Statsrådets principbeslut om trygghet av individuellt boende och tjänster för personen med utvecklingsstörning*).

⁴⁸ Slovakia, Ministry of Labour, Social Affairs and Family (*Ministerstvo práce, sociálnych vecí a rodiny*) (2011), *National action plan for the transition from institutional to community-based care in the social services system 2012-2015*, pp. 19-21.

⁴⁹ Latvia, Ministry of Welfare, Decree No.26 On the composition of the Social Services Development Council (*Rīkojums Nr. 26 "Par Sociālo pakalpojumu attīstības padomes sastāvu"*), 20 March 2014.

⁵⁰ See, for example, Bulgaria, Ministry of Labour and Social Policy (*Министерство на труда и социалната политика*) (2014), Annual report on the implementation of the Action Plan for the Porivison of Equal Opportunities for People with Disabilities 2014-2015 (*Годишен доклад за 2014 г. за изпълнението на Плана за действие за осигуряване на равни възможности за хората с увреждания 2014 – 2015 г.*).

⁵¹ Czech Republic, 2015, National Plan to Reinforce Equal Opportunities for Persons with Disabilities (*Národní plán podpory rovných příležitostí pro osoby se zdravotním postižením na období 2015–2020*); 25 May 2015, decision No 385.

⁵² Sjöblom, S. (ed.) (2014), *VAMPO-seurantaraaportti II: Katsaus Suomen vammaispoliittisen ohjelman (VAMPO) 2010-2015 toimeenpanon tilanteeseen*, National Institute for Health and Welfare, työpaperi 31/2014.

⁵³ Austria, Federal Ministry of Labour, Social Affairs and Consumer Protection (*Bundesministerium für Arbeit, Soziales und Konsumentenschutz*), National Action Plan Disability, Interim Report 2012-2015 (*Nationaler Aktionsplan Behinderung, Zwischenbilanz 2012-2015*).

⁵⁴ Slovakia, Ministry of Labour, Social Affairs and Family (*Ministerstvo práce, sociálnych vecí a rodiny SR*) (2016), *Správa o plnení opatrení vyplývajúcich z Národného programu rozvoja životných podmienok osôb so zdravotným postihnutím na roky 2014 – 2020 a návrh na jeho aktualizáciu*.

⁵⁵ This can be accessed via the [website of VALTO](#), the institutional repository for the Finnish government.

⁵⁶ 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 and UN General Assembly (2016), *Report of the Special Rapporteur on the rights of persons with disabilities*, A/HRC/34/58, 20 December 2016.

⁵⁷ Austria (1992), *Das Behindertenkonzept der österreichischen Bundesregierung*, 22 December 1992, chapter 9.2.

⁵⁸ Finland, Government Resolution On Securing Individual Housing and Services for Persons with Intellectual Disabilities (*Valtioneuvoston periaatepäätös kehitysvammaisten henkilöiden yksilöllisen asumisen ja palvelujen turvaamisesta*), 21 January 2010.

⁵⁹ Irish Health (2011), [Programme for Government Health](#).

⁶⁰ Slovakia, Act No. 448/2008 on Social Services, as amended (*Zákon č. 448/2008 Z. z. o sociálnych službách v znení neskorších predpisov*), Article 110l/3, 1 January 2014.

⁶¹ Sweden, Ministry of Health and Social Affairs (*Socialdepartementet*), Act 1997:724 (*Lag (1997:724) om avveckling av specialsjukhus och vårdhem*).

⁶² Bulgaria, Council of Ministers (*Министерски съвет*) (2014), National strategy for long-term care (*Национална стратегия за дългосрочна грижа*), 7 January 2014, p. 17.

⁶³ Hungary, Government Resolution 1257/2011 (VII. 21.) regarding the Deinstitutionalisation of Social Care Institutions for People with Disabilities (*A Kormány 1257/2011. (VII.21.) Korm. határozata a fogytékos személyek számára ápolást-gondozást nyújtó szociális intézményi férőhelyek kiváltásának stratégiájáról és a végrehajtásával kapcsolatos kormányzati feladatokról*).

⁶⁴ Romania (2015), [Minutes of the public debates on the future National Strategy 2015-2020 from 30th January 2015](#). See also: Economica.net, *Persoanele cu dizabilități vor fi dezinstituționalizate până în 2020 - Scutaru, Ministerul Muncii* (People with disabilities will be deinstitutionalised by 2020), 12 December 2014.

⁶⁵ Estonia, Ministry of Social Affairs (*Sotsiaalministeerium*) (2014), [Special Care and Welfare Development plan for 2014-2020](#) (*Erihoolekande arengukava aastateks 2014-2020*).

⁶⁶ 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. 98 (g).

⁶⁷ 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. 16 (c).

⁶⁸ Sweden, Ministry of Health and Social Affairs (*Socialdepartementet*), Act 1997:724 (*Lag (1997:724) om avveckling av specialsjukhus och vårdhem*).

⁶⁹ See [website of Lev \(2014\)](#); The Danish Institute for Human Rights, *The Ten Greatest Challenges*, Copenhagen.

⁷⁰ Aalto M., Öberg A., Rolfer B. and Hauksson J. (2015), *The right to a home of my own*, Stockholm, Nordic Centre for Welfare and Social Issues.

⁷¹ Hungary, Social Care Act, Article 66/A(2)). Information on the 2015 amendment of the Social Care Act (*Tájékoztató a szociális igazgatásról és szociális ellátásokról szóló 1993. évi III. törvény (a továbbiakban: Szt.) szociális szolgáltatásokat érintő módosításairól, valamint a kapcsolódó végrehajtási rendeletek módosításairól*), p. 2.

⁷² Estonia, Ministry of Social Affairs (*Sotsiaalministeerium*) (2014), *Special Care and Welfare Development plan for 2014-2020 (Erihoolekande arengukava aastateks 2014-2020)*, Strategic objective 2.

⁷³ Greece, Psychargos Programme (*Πρόγραμμα Ψυχαργώς*).

⁷⁴ This background paper is available on FRA's webpage on 'Rights of persons with disabilities (The right to independent living)'.

⁷⁵ European Social Network (2015), *Social planning at the local level*, Brighton; Nullmeier, F. (2011), 'Governance sozialer Dienste' in: Evers, A., Heinze, R. G. and G., Olk, T. (eds.), *Handbuch Soziale Dienste*, Wiesbaden, Springer VS, pp. 284-298.

⁷⁶ For children, the State Agency for Child Protection (*Държавна агенция за закрила на детето*) assumes responsibility.

⁷⁷ Bulgaria, Ministry of Labour and Social Policy (*Министерство на труда и социалната политика*) (2014), Annual report on the implementation of the Action Plan for the Porivison of Equal Opportunities for People with Disabilities 2014-2015 (*Годишен доклад за 2014 г. за изпълнението на Плана за действие за осигуряване на равни възможности за хората с увреждания 2014 – 2015 г.*).

⁷⁸ Germany, con_sens on behalf of Bundesarbeitsgemeinschaft der überörtlichen Sozialhilfeträger – BAGüS (2015), (*Kennzahlenvergleich Eingliederungshilfe der überörtlichen Träger der Sozialhilfe 2013*), p. 7.

⁷⁹ The 1978 Constitution stipulates in Article 148.1.20 that Autonomous Communities may assume exclusive competence in social assistance.

⁸⁰ Portugal, Decree_Law 115/2006 which stablishes the aims and the rules for the Local Social Network (*Decreto-Lei nº 115/2006 que estabelece os objetivos e o funcionamento dos órgãos da Rede Social*), 14 June 2006.

⁸¹ Slovakia, Act No. 448/2008 on Social Services, as amended (*Zákon č. 448/2008 Z. z. o sociálnych službách v znení neskorších predpisov*), Article 81, 1 January 2014.

⁸² *Ibid.*

⁸³ United Nations (UN), Committee on the Rights of Persons with Disabilities (2015), *Concluding observations on the initial report of Austria*, CRPD/C/AUT/CO/1, 30 September 2013, para. 10.

⁸⁴ CRPD Committee (2015), *Concluding observations on the initial report of Germany*, CRPD/C/DEU/CO/1, 13 May 2015, para. 6.

⁸⁵ Slovakia, Act No. 448/2008 on Social Services, as amended (*Zákon č. 448/2008 Z. z. o sociálnych službách v znení neskorších predpisov*), Article 97/1, 1 January 2014.

⁸⁶ Sweden, Ministry of Health and Social Affairs (*Socialdepartementet*), The Social Service Act (*Socialtjänstlag (2001:453)*), chapter 2 para. 6, and chapters 3 and 5; Sweden, Ministry of Health and Social Affairs (*Socialdepartementet*), *Hälsö- och sjukvårdslag (1982:763)*, paras. 2(a) and 3.

⁸⁷ United Kingdom (2014), *Care Act 2014*, 14 May 2014, s. 6 and 7.

⁸⁸ Croatia (2011), Strategy of Social Welfare Development in the Republic of Croatia 2011-2016 (*Strategija razvoja sustava socijalne skrbi u RH 2011-2016*), p.30.

⁸⁹ Croatia, Disability Ombudsman Office (*Ured pravobraniteljice za osobe s invaliditetom*)(2014); Disability Ombudsman Report 2014, p.162 (*Izvešće o radu Ureda pravobraniteljice za osobe s invaliditetom za 2014 godinu*, str.1622).

⁹⁰ Greece, National Strategic Plan on Social Integration 2015-2020 (*Εθνικό Στρατηγικό Πλαίσιο για την Κοινωνική Ένταξη*).

⁹¹ 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. 58.

⁹² 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. 26.

⁹³ UN Special Rapporteur on the rights of persons with disabilities (2017), *Report of the Special Rapporteur on the rights of persons with disabilities*, para. 58.

⁹⁴ Croatia (2011), Strategy of Social Welfare Development in the Republic of Croatia 2011-2016 (*Strategija razvoja sustava socijalne skrbi u RH 2011-2016*), p.30.

⁹⁵ Greece, National Strategic Plan on Social Integration 2015-2020 (*Εθνικό Στρατηγικό Πλαίσιο για την Κοινωνική Ένταξη*).

⁹⁶ 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. 15 (k).

⁹⁷ Denmark, the Act on Social Services, Consolidated act no. 150 of 16 February 2015 (*Bekendtgørelse af lov om Social Service, nr. 150 af 16. februar 2015*).

⁹⁸ Finland, National Institute for Health and Welfare (*Terveystieteiden tutkimuskeskus/Institutet för hälsa och välfärd*), 'Asunnon vaihtaminen' in the Handbook of Disability Services (*Vammaispalvelujen käsikirja*).

⁹⁹ United Kingdom (2014) *Care Act 2014*, 14 May 2014, ss. 39 and 38. Further detailed provisions can be found in two specific regulations from 2014: the Care and Support (Continuity of Care) Regulations and the Care and Support (Disputes between Local Authorities) Regulations.

¹⁰⁰ For more information, see FRA's [webpage on this research project](#).

¹⁰¹ Bulgarian Helsinki Committee (2017), *Alternative report about the rights of persons with disabilities in Bulgaria under the UN convention on the rights of persons with disabilities*, pp. 53 and 82. Bulgarian National Network for Children (2016), *Report card 2016. What is the average government score for childcare*, pp. 29 and 34.

¹⁰² European Parliament Committee on Petitions (2016), *Mission report and recommendations following the fact-finding visit to Slovakia of 22-23 September 2016*, 29 November 2016.

¹⁰³ Council Regulation (EC) No. 168/2007 of 15 February 2007 establishing a European Union Agency for Fundamental Rights, OJ L 53/1, 22 February 2007, Art. 2.

¹⁰⁴ FRA (2014), *The right to political participation for persons with disabilities: human rights indicators*, Luxembourg, Publications Office. See also: FRA (2010), *The right to political participation of persons with mental health problems and persons with intellectual disabilities*, Luxembourg, Publications Office.

¹⁰⁵ FRA (2013), *Legal capacity of persons with intellectual disabilities and persons with mental health problems*, Luxembourg, Publications Office.

¹⁰⁶ FRA (2012), *Involuntary placement and involuntary treatment of persons with mental health problems*,

¹⁰⁷ FRA (2012), *Choice and control: the right to independent living*, Luxembourg, Publications Office.

¹⁰⁸ FRA (2011), *The legal protection of persons with mental health problems under non-discrimination law*, Luxembourg, Publications Office.

¹⁰⁹ FRA (2015), *Violence against children with disabilities: legislation, policies and programmes in the EU*, Luxembourg, Publications Office.

¹¹⁰ This background paper is available on FRA's webpage on 'Rights of persons with disabilities (The right to independent living)'.

¹¹¹ The indicators are based on the human rights model developed by the OHCHR. See: UN, OHCHR (2012), *Report on Human rights indicators: A Guide to Measurement and Implementation*, HR/PUB/12/5.

¹¹² See FRA's webpage on the [Article 19 indicators](#).

¹¹³ UN, OHCHR (2012), *Report on Human rights indicators: A Guide to Measurement and Implementation*, HR/PUB/12/5.

¹¹⁴ FRA (2014), *The right to political participation for persons with disabilities: human rights indicators*, Luxembourg, Publications Office.

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 a meaningful and sustainable shift from institutional to community-based living arrangements. This, in turn, calls for both deinstitutionalisation strategies and for effectively coordinating the different actors involved in making deinstitutionalisation a reality. However, putting in place political commitments and implementation structures is just one element of the process. The other two reports in FRA's three-part series dedicated to this topic look at other important factors: budgeting and financing, and measuring outcomes for persons with disabilities. Taken together, the three reports provide important insights that can support ongoing efforts to make independent living a reality for persons with disabilities.