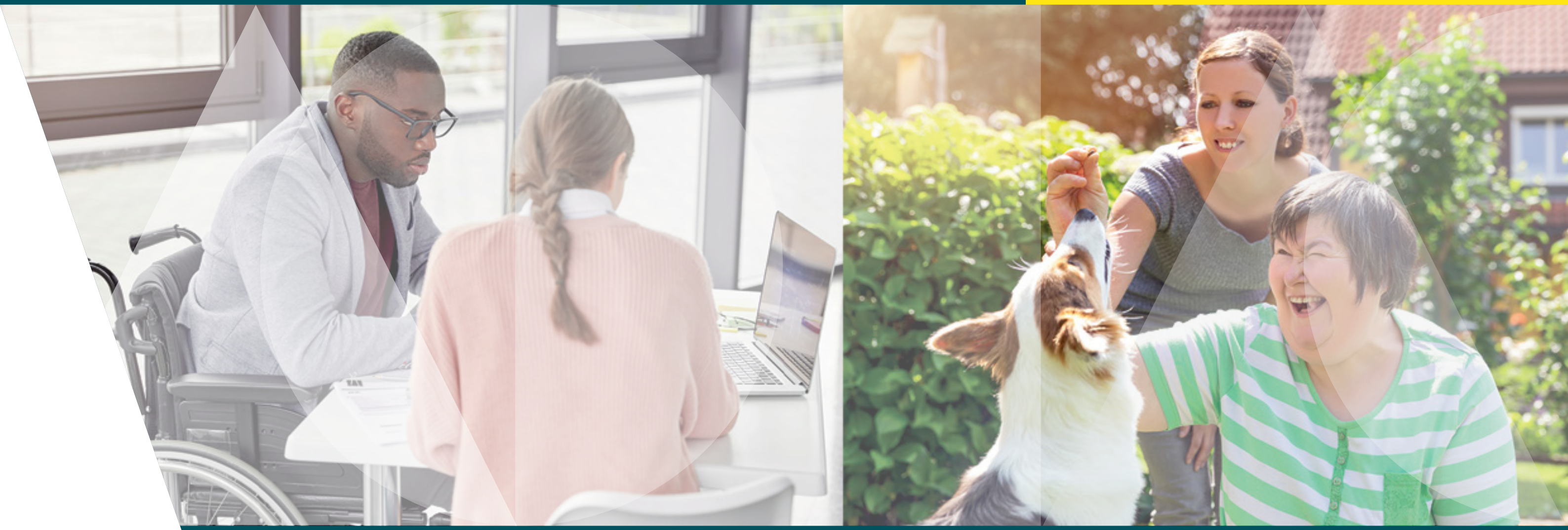
EQUALITY



From institutions to community living for persons with disabilities: perspectives from the ground

EUROPEAN UNION AGENCY
FOR FUNDAMENTAL RIGHTS

Photo (cover & inside): © [from left to right] Stock.adobe.com-Wayhome Studio;Stock.adobe.com-M.Dörr & M.Frommherz.

Luxembourg: Publications Office of the European Union, 2018

FRA – print:	ISBN 978-92-9474-220-9	doi:10.2811/115413	TK-02-18-998-EN-C
FRA – web:	ISBN 978-92-9474-219-3	doi:10.2811/231399	TK-02-18-998-EN-N

EUROPEAN UNION AGENCY
FOR FUNDAMENTAL RIGHTS

From institutions to community living for persons with disabilities: perspectives from the ground

Foreword

How would you feel if you were not able to decide when to eat, where to buy your groceries, at what time to leave the house, or how to get to a friend's place? We make such basic decisions all the time, and take for granted that we do so ourselves. But people with disabilities who live in institutions do not share this freedom.

The Convention on the Rights of Persons with Disabilities commits both the EU and all of its Member States to realising the right of persons with disabilities to live independently in the community – which includes achieving deinstitutionalisation for those residing in institutional settings. Yet FRA's research underscores that much remains to be done to make this a reality in practice.

This report presents the main insights gained during fieldwork on the drivers of and barriers to deinstitutionalisation. Focusing on the local level and reaching out to a diverse set of actors, the research explored what does and does not work on the ground.

Most importantly, it gives voice to people rarely heard in these discussions: people with disabilities themselves. Their input offers powerful and direct testimony about the transformational power of deinstitutionalisation. In addition, the research involved the families of individuals going through the transition to community-based living, members of local communities, and the various people responsible for designing the process and implementing it on a daily basis.

The main lessons are clear. To bridge the gap between rhetoric and reality, we must truly want to achieve deinstitutionalisation. We also need to instil positive attitudes towards people with disabilities. The many different actors involved in the process must talk to each other and work together. Guidance that enables those involved to turn policy into practice is also crucial. Finally, we have to make sure that the services people with disabilities need are accessible in the community.

The report shows that there is a long way to go – but also outlines practical, concrete and positive ideas that can spur successful deinstitutionalisation. We hope it gives policymakers the energy and inspiration needed to take this important work forward – with the ultimate goal of ensuring that people with disabilities can live independently in the community on an equal basis with others.

Michael O'Flaherty
Director

Contents

FOREWORD ... 3

KEY FINDINGS AND FRA OPINIONS ... 7

INTRODUCTION ... 13

1 CONTEXT OF DEINSTITUTIONALISATION ... 19
  1.1. Status of deinstitutionalisation in the five Member States ... 20
  1.2. Legal and policy framework for deinstitutionalisation ... 22
    National legal and policy frameworks for deinstitutionalisation ... 22
    Local legal and policy frameworks for deinstitutionalisation ... 24
  1.3. Organisation of deinstitutionalisation ... 25
  1.4. Funding for the deinstitutionalisation process ... 26

2 COMMON UNDERSTANDING OF WHAT DEINSTITUTIONALISATION AND INDEPENDENT LIVING MEAN ... 29
  2.1. Key terms and concepts ... 30
  2.2. Impact of deinstitutionalisation ... 32

3 ESSENTIAL FEATURES OF THE DEINSTITUTIONALISATION PROCESS ... 35
  3.1. Commitment to deinstitutionalisation ... 36
    Driver 1: National political commitment to deinstitutionalisation ... 37
    Driver 2: Commitment at local level ... 39
    Driver 3: External pressure to hasten deinstitutionalisation ... 39
    Driver 4: Persons with disabilities demanding deinstitutionalisation ... 40
    Barrier 1: Insufficient, difficult to access or poorly assigned funding ... 41
    Barrier 2: Vested interests trying to block deinstitutionalisation ... 43
    Barrier 3: Deprivation of legal capacity ... 43
  3.2. A change in attitudes towards persons with disabilities ... 44
    Driver 1: Changes in public attitudes towards persons with disabilities ... 45
    Driver 2: Media and individual stories redefining public perceptions of people with disabilities ... 47
    Driver 3: Changes in staff attitudes towards people with disabilities ... 47
    Barrier 1: Institutional models of 'care' persisting ... 48
    Barrier 2: Learned dependence of persons with disabilities ... 49
    Barrier 3: Family resistance to deinstitutionalisation ... 49
  3.3. Active cooperation between the people involved in the deinstitutionalisation process ... 50
    Driver 1: Cooperation at local level ... 51
    Driver 2: Cooperation with the families of persons with disabilities ... 52
    Driver 3: Cooperation with actors bringing innovation and change ... 52
    Barrier 1: Lack of cooperation between and across sectors ... 53
    Barrier 2: Lack of cooperation between different levels of governance ... 54
    Barrier 3: Lack of cooperation with the local community ... 54
  3.4. Availability of guidance to support the deinstitutionalisation process ... 55
    Driver 1: Pilot projects showcasing how deinstitutionalisation works in practice ... 55
    Driver 2: Staff (re-)training and recruitment ... 56
    Barrier 1: Insufficient guidance from national to local level ... 57
    Barrier 2: Insufficient preparation and information for persons with disabilities and their families ... 57
  3.5. Practical organisation of the deinstitutionalisation process ... 58
    Driver 1: Individual support plans for persons with disabilities ... 60
    Driver 2: Developing independent living skills ... 60
    Barrier 1: Lack of specialised support services in the community for people with disabilities ... 62
    Barrier 2: Unavailable or inaccessible general services ... 64
    Barrier 3: Inflexible rules and regulations on the provision of services to people with disabilities ... 66
    Barrier 4: Lack of employment opportunities for persons with disabilities ... 67
    Barrier 5: Staff working conditions ... 68
  3.6. Cross-cutting issues ... 69
    Impact of different types and degrees of impairment on the deinstitutionalisation process ... 69
    Impact of age on the deinstitutionalisation process ... 70

4 MEASURES TO ACHIEVE SUCCESSFUL DEINSTITUTIONALISATION ... 77
  4.1. Commitment to deinstitutionalisation ... 77
  4.2. A change in attitudes towards persons with disabilities ... 79
  4.3. Active cooperation between the people involved in the deinstitutionalisation process ... 80

4.4. Availability of guidance to support the deinstitutionalisation process ... 81
4.5. Practical organisation of the deinstitutionalisation process ... 82
ANNEX 1: OVERVIEW OF DRIVERS OF AND BARRIERS TO DEINSTITUTIONALISATION ... 84
ANNEX 2: METHODS AND DESIGN ... 86
Selecting the Member States for the fieldwork ... 86
The stages of the fieldwork research ... 87
Validating the findings of the fieldwork ... 90

Key findings and FRA opinions

"They have simply realised that their life is similar to ours, you see? [...] And that really makes them happier."
(Slovakia, employee of an institutional service)

By ratifying the CRPD, the EU and all 28 of its Member States have committed to realising the right of persons with disabilities to live independently in the community. This includes achieving deinstitutionalisation for those persons with disabilities living in institutional settings. This research shows, however, that much remains to be done to make deinstitutionalisation a reality in practice. More than one million Europeans with disabilities continue to live in institutions.[1] Both they, and many people with disabilities already living in the community, are prevented from realising their potential by a lack of available and affordable support services, persisting stigma and discrimination, and inaccessible environments.

The following FRA opinions build on the findings of FRA's fieldwork to examine the drivers of and barriers to the deinstitutionalisation process, as experienced by the actors responsible for designing and implementing it, and by the individuals and families going through the transition process (For an overview of the key drivers and barriers emerging from the research, see Annex 1). The opinions address the five essential features of successful deinstitutionalisation that FRA identified on the basis of the research findings (see Table 1).

Commitment to deinstitutionalisation and a change in attitudes emerge from the research as the most important features of successful deinstitutionalisation. As with all the features, they are closely interlinked: changes in attitudes towards persons with disabilities drive commitment to deinstitutionalisation, whereas commitments on paper mean little unless attitudes shift. Active cooperation, availability of guidance and practical organisation are the enabling elements that facilitate efforts to make deinstitutionalisation a reality. Both active cooperation and availability of guidance ensure that political commitment to deinstitutionalisation is carried through, and that changes in attitudes are fostered through a common goal and vision for independent living. Practical organisation, composed of a series of interdependent components, involves the everyday elements that enable life in the community. These are often difficult to put in place but invisible when working smoothly.

The FRA opinions primarily address policymakers in the EU institutions and the national administrations of EU Member States. The report also contains a wealth of other practical suggestions proposed by participants in

Table 1: Key features of a successful deinstitutionalisation process

Key feature	Explanation
Commitment to deinstitutionalisation	• On the part of authorities at the national, regional and/or local levels • On the part of people involved in the process, that is, staff of services for persons with disabilities, families, persons with disabilities
A change in attitudes towards persons with disabilities	• Towards deinstitutionalisation and how services and support are provided to persons with disabilities • Towards empowering persons with disabilities to live independently
Active cooperation between the people involved in deinstitutionalisation	• Between different levels of governance (national, regional, local) • Between different sectors involved in the deinstitutionalisation process (for example, health, housing, employment) • With families and persons with disabilities, the local community and disabled persons' organisations
Availability of guidance to support deinstitutionalisation	• Tools on how to implement the deinstitutionalisation process • Training and re-training of staff who work on the deinstitutionalisation process • Pilot projects on deinstitutionalisation
Practical organisation of deinstitutionalisation	• Organisation and implementation of the deinstitutionalisation process • Availability of support services in the community • Preparing people involved in the process for deinstitutionalisation

Source: FRA, 2018

---

[1] Mansell, J., Knapp, M., Beadle-Brown, J. and Beecham, J. (2007), *Deinstitutionalisation and community living – outcomes and costs: report of a European Study*. Volume 2: Main Report. Canterbury: Tizard Centre, University of Kent.

the research. These are relevant to a wider audience, including local and regional authorities, managers and staff of services for persons with disabilities, disabled persons organisations, and persons with disabilities and their families. Many of these opinions echo those in previous FRA reports on the rights of persons with disabilities, in particular *From institutions to community living: Parts I, II and III* (2017), *Violence against children with disabilities: legislation, policies and programmes in the EU* (2015), and *Choice and control: the right to independent living* (2012).

When responding to the opinions, EU institutions and Member States should ensure that they fully involve persons with disabilities, through their representative organisations, as required by Article 4(3) of the CRPD. Establishing or strengthening existing consultative mechanisms, such as advisory bodies that include persons with disabilities and their representative organisations, is one way to ensure the full participation of persons with disabilities in the design, implementation and monitoring of all efforts to further deinstitutionalisation.

Common understanding of what deinstitutionalisation and independent living mean

Deinstitutionalisation entails fundamental changes in how and where services for persons with disabilities are provided, participants emphasised. It involves both a physical relocation from institutional settings to accommodation in the community, and a transformation in the culture shaping how services are delivered, so that they respond to individual needs and preferences. To ensure that community-based services promote autonomy and inclusion for persons with disabilities, these two elements must work in tandem.

However, understandings of these key terms across the participant groups often diverge from the definitions provided by the CRPD Committee in its General Comment on Article 19 of the convention, the research shows. Some participants saw independent living as meaning that persons with disabilities live in the community with limited or no financial and staff support. Others, particularly at the local level, felt that independent living is not appropriate for those with severe impairments or challenging behaviour. This is partly because of a lack of suitable community-based services for people with complex needs. Nevertheless, several participants noted that such attitudes often mean that deinstitutionalisation processes start with those with less severe impairments, to the detriment of individuals with complex needs.

These different understandings prevent a common approach to putting deinstitutionalisation into practice. They also create frustration among the many different stakeholders involved in the process. Local-level participants felt they are tasked to implement policy that does not reflect reality on the ground, for example. Representative organisations of persons with disabilities meanwhile worried that staff of disability and other social services, and policymakers, do not incorporate rights-based approaches in their work. This can impede successful transition processes, as different actors take different steps to implement their own understanding of independent living. The *Common European Guidelines on the transition from institutional to community-based care* aim to address this by providing policymakers at all levels with practical, rights-based advice on how to achieve deinstitutionalisation.[2]

Despite these differences, all the participants with personal experience of deinstitutionalisation – ranging from persons with disabilities to families, staff and community members – emphasised the positive impact it had on their lives. For persons with disabilities, it prompts greater choice and control, more personal space and privacy, and better relationships with staff, families and the wider community.

FRA opinion 1

EU Member States should ensure that their laws, policies and programmes on deinstitutionalisation are in line with the concept of independent living set out in the CRPD. To do this, they can draw on the definitions set out in the general comment on Article 19 of the CRPD. Laws, policies and programmes should incorporate all persons with disabilities, irrespective of the type and severity of impairment.

Member States could make use of the Common European Guidelines on the transition from institutional to community-based care *to inform trainings on key concepts for stakeholders responsible for deinstitutionalisation policy and implementation. The European Commission should support the development of a common understanding of deinstitutionalisation in actions supported by the European Structural and Investment Funds by further promoting use of the* Common European Guidelines*, particularly at the national level.*

---

[2] EEG (2012), *Common European Guidelines on the transition from institutional to community-based care*.

Commitment to deinstitutionalisation

Participants across countries and stakeholder groups agreed on the crucial importance of commitment to deinstitutionalisation across all levels of governance and among all stakeholders involved in the process. This commitment can derive from outside pressure, for example from the media or the EU, from individual stakeholders committed to deinstitutionalisation, and from the determined self-advocacy of persons with disabilities. Participants emphasised that commitment to developing laws and policies must be matched by a willingness to take the sometimes difficult steps to implement them.

At the national level, the research found strong signals of political will to implement the CRPD through legal reforms and targeted deinstitutionalisation strategies supported by adequate funding and actions to implement. Two-thirds of EU Member States have either adopted a dedicated strategy on deinstitutionalisation or included measures for deinstitutionalisation in a broader disability strategy, FRA's report *From institutions to community living: Part 1 – commitments and structures* indicates. Participants welcomed these commitments, but expressed frustration at delays in their implementation. Many stakeholders at the local level argued that, in some cases, local commitment to deinstitutionalisation is stronger than national commitment. They felt that such local-level commitment can serve to inform, strengthen and campaign for greater national commitment.

FRA opinion 2

All EU Member States should adopt deinstitutionalisation strategies. These strategies should include specific targets and clear deadlines, and be adequately financed. They should also be sufficiently broad in 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.

The European Commission should include comprehensive and explicit measures, within its areas of competence, for the protection, promotion and fulfilment of the right to independent living in the post-2020 European disability strategy. To deliver on commitments contained in the European Pillar of Social Rights, the EU legislature should proceed swiftly with concrete legal initiatives to implement the principles and rights enshrined in the Pillar.

Funding that is insufficient, poorly spent or difficult to access undermines efforts to achieve successful deinstitutionalisation, participants argued. They highlighted the need to shift funding from institutional to community-based services, and to provide additional resources to cover the costs of running institutional and community-based services in parallel during the transition phase. Individualised financial support models, such as direct payments and personal budgets, promote greater choice and control for persons with disabilities, they felt.

Many participants in Bulgaria and Slovakia highlighted the importance of European Structural and Investment Funds (ESIF) in funding deinstitutionalisation. However, using ESIF presents several practical challenges, they pointed out: these provide important lessons for the post-2020 funding period. ESIF's project-based approach means that funding is time bound, which makes the sustainability of projects questionable if national funding is either not in place or insufficient to continue the activity when the ESIF project ends. In addition, restrictions on which organisations ESIF can finance, and a failure to take full advantage of the different activities that ESIF can fund, can mean that more innovative practices struggle to access financing.

FRA opinion 3

EU Member States, and the European Commission when ESIF are involved, should allocate resources for the prompt deinstitutionalisation of persons with disabilities. They should phase out investment in institutions and instead sufficiently fund services in the community that persons with disabilities guide and control. They should pay particular attention to developing personalised financial support options. These actions should have clear timelines and be subject to robust and independent monitoring.

EU institutions and Member States should take advantage of the full range of EU financial tools to support the transition from institutional to community-based support. This should include training and capacity building for staff, developing individual support plans and funding home adaptations and other infrastructure. The EU legislature should ensure that the post-2020 ESIF regulations build on the current legal framework and contain strong fundamental rights guarantees to ensure that the EU fully respects its human and fundamental rights obligations under the CRPD and the Charter for Fundamental Rights.

Depriving people of legal capacity both leads to and lengthens institutionalisation by preventing people with disabilities from making choices about their lives, participants reported. It also has an impact on how people with disabilities are viewed, participants highlighted, because it casts them as being unable to express their preferences. This reinforces the findings of FRA's report *Legal capacity of persons with intellectual disabilities and persons with mental health problems,* in which participants reported that their guardians took decisions over where they should live.[3]

FRA opinion 4

In line with their obligations under Article 12 of the CRPD, EU Member States should abolish all substituted decision-making schemes and develop alternative supported decision-making mechanisms that empower people with disabilities to make decisions about their lives.

A change in attitudes towards persons with disabilities

Attitudes towards persons with disabilities are generally improving, participants felt. At the societal level, this is in large part a result of people with disabilities gradually becoming more visible. This contributes to a positive cycle: as people with disabilities become more visible and active in the community, communities are more welcoming to them, making the transition process easier. At the individual level, positive attitudes among staff of disability services empower people with disabilities to transition to the community and set a positive example for other colleagues.

However, strongly embedded beliefs that people with disabilities should be 'looked after' and 'cared for' persist among staff, family members and, in some cases, persons with disabilities themselves. When staff hold them, such attitudes both prevent people with disabilities from leaving institutions, and lead to institutional approaches being carried over into community-based services. Among families, concerns about a lack of appropriate support services in the community fuel fears for the safety and security of their relatives if they start living independently in the community. This contributes to resistance towards deinstitutionalisation efforts. For persons with disabilities, the lack of opportunities in institutions to acquire and develop everyday life skills can leave them feeling ill-equipped for life in the community.

FRA opinion 5

EU institutions and Member States should develop campaigns at the national and local levels to raise awareness of the right of persons with disabilities to live independently and be included in the community. The campaigns should include activities targeting the general public, national and local public officials, and service providers, as well as persons with disabilities and their families. They should focus on reshaping perceptions of disability, promoting diversity and tackling the stigma around disability. Any campaign should be fully accessible to persons with disabilities.

Participants felt that positive stories of people with disabilities living ordinary lives in the community help to reshape perceptions of disability and counter the 'fear of the unknown'. These success stories are important both at the societal level, to help shape public attitudes, and at the individual level, where concrete examples of people transitioning from institutional to community-based services can help alleviate doubts that deinstitutionalisation is possible.

FRA opinion 6

EU institutions and Member States should work with media and other communication providers to develop and disseminate positive images of persons with disabilities living independently and being included in their communities. These could include stories of persons with disabilities gaining choice and control over their lives through deinstitutionalisation.

Active cooperation between the people involved in the deinstitutionalisation process

Deinstitutionalisation involves a wide range of actors. Systematic coordination and effective cooperation between them is essential. They include public authorities at the national, regional and local levels, and across sectors ranging from disability services to health, education and employment, as well as third sector organisations. But it also encompasses those whose involvement is personal rather than professional: families, local communities and persons with disabilities.

Participants spoke extensively about the importance of cooperation, but reported that it is often lacking in practice. They pointed to gaps in cooperation both between different levels of government and across different sectors, driven in part by a tendency for stakeholders to focus only on their specific role in the process and a lack of clarity about which bodies are responsible for what part of the transition process.

---

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

Establishing working groups bringing together a wide range of relevant actors can improve coordination, cement cooperation and support a holistic approach to deinstitutionalisation, participants felt.

FRA opinion 7

EU Member States should develop mechanisms and processes to ensure effective coordination and cooperation between municipal, local, regional and national authorities, and across relevant sectors, including housing, employment, health and social services. This could include establishing a working group to coordinate actions and assess progress towards deinstitutionalisation, composed of representatives of different governance levels and sectors, service providers, and persons with disabilities and their family members.

Some local-level participants reported feeling excluded from decision-making processes. They argued that this left national policymakers, in particular, without access to knowledge and experience of the everyday process of deinstitutionalisation. This increases the risk of developing policies that prove unworkable in practice.

FRA opinion 8

When developing and implementing policies, action plans and guidelines on deinstitutionalisation, EU Member States should consult and actively engage frontline practitioners with experience and knowledge of implementing the transition from institutional to community-based support.

Many participants pointed to the important contribution of so-called third sector organisations, such as associations, non-profit organisations, cooperatives, social enterprises and non-governmental organisations (NGOs), throughout the deinstitutionalisation process. At the policy level, they credited these organisations with achieving legislative reforms through their advocacy works. In implementation terms, they both pilot new and innovative services and provide valued expert advice on how to achieve deinstitutionalisation.

FRA opinion 9

EU Member States should actively engage relevant third sector organisations in the design and delivery of deinstitutionalisation policies and programmes.

Availability of guidance to support the deinstitutionalisation process

Many participants spoke of struggling to translate the principles of autonomy, choice and control into practice. Practitioners reported an absence of guidance from the national level on how to apply law and policy to the realities they experience in their daily work. They identified more concrete and better targeted guidance as key to enabling them to implement a person-centred approach in practice. Participants also highlighted that guidance should be complemented by opportunities to see and discuss good practices in person. Learning exchanges allow stakeholders to acquire new knowledge and ideas on how to design and implement deinstitutionalisation, they noted.

Gaps in guidance to persons with disabilities and their families left some participants feeling unclear about what would happen to them and when during the deinstitutionalisation process, and reduced their ability to participate actively in the process.

FRA opinion 10

EU Member States should develop practical guidelines, protocols and toolkits on how to implement deinstitutionalisation, in collaboration with people with disabilities and frontline staff. This guidance should focus on providing practitioners with concrete advice to support their daily work, including how to identify individual needs, prepare support plans and develop independent living skills in people with disabilities. This could be accompanied by guidance for persons with disabilities and their families on the main stages of the deinstitutionalisation process.

EU Member States should facilitate learning exchanges between localities, regions and countries. The European Commission should further develop and strengthen mechanisms to foster exchange of good practices between EU Member States. This should incorporate funding, including through the use of ESIF, short-term field visits and longer-term professional exchanges to enable peer-to-peer learning.

Participants highlighted training for staff as a critical component of transforming institutional practices into person-centred approaches based on an independent living philosophy. This encompasses both training for new staff entering disability services and, in particular, re-training for existing staff on how to change the way they deliver services to meet the requirements of the CRPD. Training for staff working in other sectors such as health, employment and transport is also necessary. Participants emphasised that training should be on-going and based on practical examples.

FRA opinion 11

EU Member States should provide compulsory training for all actors involved in the deinstitutionalisation process on how to embed the principles of choice and control for persons with disabilities in their work. They should pay particular attention to training frontline staff, whether newly recruited or long-serving, to implement person-centred approaches in the delivery of services.

Practical organisation of the deinstitutionalisation process

Participants emphasised two core elements of organising deinstitutionalisation in practice: developing specialised support services in the community, and making general services available to the public accessible to persons with disabilities. Both are, however, lacking. Specialised support services in the community include personal assistance, housing adaptations, technical aids, sign language interpreters, peer support and day-care centres, among others.

The absence of appropriate community-based disability services prevents people from leaving institutions, as they remain the only source of essential support. It also impedes the full realisation of independent living in the community, by curtailing the ability of people with disabilities to exercise choice and control over their lives. Participants reported that many community-based services are based on a 'one size fits all' approach, rather than being tailored to the needs and wishes of individuals. Efforts to develop more responsive services are sometimes undermined by overly rigid rules and regulations, participants report. Developing individual support plans for persons with disabilities is one way to help these services better their individual needs.

FRA opinion 12

EU Member States should ensure that a range of community-based living arrangements are available to give persons with disabilities, regardless of type and degree of impairment, a meaningful choice over where to live.

EU Member States should ensure that adequate, good-quality and freely chosen personalised support for independent living is available for all persons with disabilities. This support should be available regardless of an individual's living arrangements. It should also be under the user's control. EU Member States should pay particular attention to developing personal assistance services.

Housing, healthcare and transport services are often not accessible to persons with disabilities or unresponsive to their needs. Participants emphasised that being unable to access these services, and facing discrimination and prejudice when trying to do so, deepens the isolation of people with disabilities. This is compounded by the difficulties of accessing employment on the open labour market, which deprive people with disabilities of a route to financial stability and social inclusion.

FRA opinion 13

The EU and its Member States should develop, spread awareness of and monitor through inspections the implementation of minimum standards and guidelines for the accessibility of facilities and services that are open or provided to the public. The minimum standards should encompass the accessibility needs for all persons with disabilities.

EU Member States should develop measures to ensure non-discrimination on the grounds of disability in employment and occupation, in line with their obligations under the Employment Equality Directive and in cooperation with their national equality bodies. They should develop programmes to facilitate equal access to employment on the open labour market for people with disabilities.

For persons with disabilities themselves, participants emphasised the role of opportunities to develop independent living skills such as cooking, shopping or cleaning, which are not developed when living in institutionalised settings. Participants highlighted that this can help make the prospect of deinstitutionalisation less daunting for people with disabilities and reduce families' concerns that their relatives lack the everyday skills necessary for living independently in the community.

FRA opinion 14

EU Member States should establish programmes to develop and strengthen the independent living skills of persons with disabilities, in close cooperation with persons with disabilities and their representative organisations. Member States should ensure that all such activities are fully accessible to all persons with disabilities, irrespective of type and degree of impairment.

Introduction

Figure 1: What people with disabilities say about moving to live in the community

"I'm a new girl now, I know what I want and everything."
(Claire, Ireland)

"What is a good living situation? When you can decide things by yourself, that is a good living situation."
(Mikko, Finland)

"I have a life. […] Having a house feels like I won the lottery."
(Romeo, Italy)

"We had no [financial] resources, no freedom to buy something, to go out: we stayed locked. And now we feel free!"
(Ivan, Bulgaria)

"I am particularly happy about being able to make my own plans, decisions and choices, especially over the weekends."
(Paul, Slovakia)

Note: All names are pseudonyms.
Source: FRA, 2018

For most people in the EU, the local community is the everyday backdrop to their lives. Choices about when to go out, what to eat, where to shop or how to get to a friend's house are so routine that people make them without noticing. For many people with disabilities, however, this is not the case. People with disabilities living in institutions, in particular, are often prevented from making basic decisions about their lives. Everyday choices about when to have dinner, when to go to sleep or who to live with are made by others on their behalf. This drastically curtails the choice and control they can exercise over their lives, and prevents them from participating in the lives of their communities.

The exclusion and isolation stemming from institutionalisation of persons with disabilities has prompted a recognition of the need to ensure that people with disabilities can live in the community on an equal basis with others. FRA evidence consistently shows that ratifying the United Nations Convention on the Rights of Persons with Disabilities (CRPD) has spurred wide-ranging legal and policy reforms concerning the right to independent living.[4] Most EU Member States have introduced new or amended legislation to promote choice of living arrangements, personalised support, and access to community services and facilities open to the general population.[5]

Making the transition from institutional to community-based forms of living and support arrangements in practice, however, is proving a considerable challenge.[6] Concerns over cost, the impact on staff currently employed in institutions, poor coordination between different levels and sectors of government, lack of knowledge about how to implement the transition in practice and a residual perception that many people with disabilities are 'unable' to live in the community each impede efforts to achieve independent living.

This report aims to support ongoing efforts to bridge the gap between the promise of law and policy, and the reality on the ground. Drawing on the experiences of people directly involved in the transition process, including persons with disabilities and their families, this report looks at how this transition can be achieved.

---

[4] See: European Union Agency for Fundamental Rights (FRA) (2015), *Implementing the UN CRPD: An overview of legal reforms in EU Member States*, FRA's annual Fundamental Rights Reports.

[5] For further information, see *FRA's indicators on Article 19 of the CRPD*.

[6] See: FRA (2017), *From institutions to community living: Part I: commitments and structures*, Luxembourg, Publications Office of the European Union (Publications Office); FRA (2017), *From institutions to community living - Part II: funding and budgeting*, Luxembourg, Publications Office; FRA (2017), *From institutions to community living: Part III: outcomes for persons with disabilities*, Luxembourg, Publications Office; FRA (2012), *Choice and control: the right to independent living*, Luxembourg, Publications Office.

It identifies the drivers that push the transition process forward and the barriers that hold it back, providing both policymakers and practitioners with evidence to support successful transition processes.

What is deinstitutionalisation?

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."[7] 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.[8] This report uses 'the transition from institutional to community-based support' interchangeably with 'deinstitutionalisation'.

Achieving deinstitutionalisation is not limited to changing the place or type of residence. Instead, it entails a profound shift from environments characterised by an 'institutional culture' of routine and rules, 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."[9]

What does the law and policy say?

Article 19 of the Convention on the Rights of Persons with Disabilities: Living independently and being included in the community

States Parties to the present Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;

b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;

c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

Article 26 of the Charter of Fundamental Rights of the European Union: Integration of persons with disabilities

The Union recognises and respects the right of persons with disabilities to benefit from measures designed to ensure their independence, social and occupational integration and participation in the life of the community.

Article 15 of the Council of Europe European Social Charter (revised): The right of persons with disabilities to independence, social integration and participation in the life of the community

Disabled persons have the right to independence, social integration and participation in the life of the community.

---

[7] UN 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. 25 and FRA (2017), *From institutions to community living- Part II: funding and budgeting*, Luxembourg, Publications Office.

[8] See: European Expert Group on the transition from institutional to community-based care (EEG) (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/GC/5, 27 October 2017.

[9] EEG (2012), Common European Guidelines on the Transition from Institutional to Community-based Care, p. 27.

All 28 EU Member States and the EU itself have acceded to the CRPD.[10] Article 19 of the CRPD sets out the right of people with disabilities to live independently and be included in the community. It lies at the heart of the convention and is the core global standard for independent living. It represents "the sum of the various parts of the convention" and brings together the principles of equality, autonomy and inclusion.[11]

> *"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*

As with all the rights enshrined in the convention, Article 19 does not set out a new right for people with disabilities.[12] Rather, it spells out explicitly that people with disabilities, regardless of the type and severity of their impairment, have an equal right to live independently and be included in the community. This report 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 contrasts "living in the community" with "isolation or segregation from the community", and breaks down "full inclusion and participation" 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 (Article 19(a));
- **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 (Article 19(b));
- **Availability of community services and facilities:** ensuring that existing public services are inclusive of persons with disabilities (Article 19(c)).[13]

The Committee on the Rights of Persons with Disabilities (CRPD Committee) further elaborated on the core elements of Article 19 and how it should be implemented in practice in its 2017 General Comment.[14] Many of the key elements of the CRPD Committee's guidance are reflected in the findings of this research.

> *"Independent living/living independently means that individuals with disabilities are provided with all necessary means enabling them to exercise choice and control over their lives and make all decisions concerning their lives. Personal autonomy and self-determination is fundamental to independent living, [and is] linked to the development of a person's identity and personality: where we live, with whom, what we eat, whether we like to sleep in or go to bed late at night, be inside or outdoors, have a tablecloth and candles on the table, have pets or listen to music. Such actions and decisions constitute who we are."*
>
> *CRPD Committee (2017), General comment No. 5 (2017) on living independently and being included in the community, CRPD/C/GC/5, 27 October 2017, para. 16*

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".[15] This implies that the choice of where to live set out in Article 19 (a) does not encompass the choice to live in an institutionalised setting, as these should be replaced with "independent living support services".[16]

Furthermore, the Committee has stressed that "[i]nstitutionalization is discriminatory as it demonstrates a failure to create support and services in the community for persons with disabilities who are

---

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

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

[12] Arnadóttir, O. M.., & Quinn, G. (2009), The *UN Convention on the rights of persons with disabilities: European and Scandinavian perspectives*, Leiden and Boston, Martinus Nijhoff; European Foundation Centre (2010), *Study on challenges and good practices in the implementation of the UN Convention on the rights of persons with disabilities*, Brussels, European Foundation Centre.

[13] 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 UN 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.

[14] Committee on the Rights of Persons with Disabilities (CRPD Committee) (2017), *General comment No. 5 (2017) on living independently and being included in the community*, CRPD/C/GC/5, 27 October 2017.

[15] See, in particular, CRPD Committee (2017), *General comment No. 5 (2017) on living independently and being included in the community*, CRPD/C/GC/5, 27 October 2017, para. 16 (c). Many organisations, including FRA, submitted written comments on the draft General Comment.

[16] CRPD Committee (2017), *General comment No. 5 (2017) on living independently and being included in the community*, CRPD/C/GC/5, 27 October 2017, para. 42. See also many of the submissions to the CRPD Committee on its draft General Comment

forced to relinquish their participation in community life to receive treatment."[17] The Committee states that eliminating discrimination requires States parties "to repeal or reform policies, laws and practices that prevent persons with disabilities from, for example, choosing their place of residence, securing affordable and accessible housing, renting accommodation or accessing such general mainstream facilities and services as their independence would require".[18] As this research shows, these are crucial aspects of successful deinstitutionalisation processes.

Article 19 includes both elements that are immediately applicable and those subject to so-called 'progressive realisation'. The right to choose where and with whom to live, set out in Article 19 (a) of the CRPD, applies immediately.[19] In contrast, the rights to access individualised support services, and community services and facilities, under Article 19 (b) and (c) can be implemented over time. Nevertheless, States Parties to the convention must take measures to realise these rights "to the maximum of [their] available resources" and avoid any retrogressive steps.[20] Article 19 also places both negative obligations – to refrain from certain acts – and positive obligations – to take steps to realise rights – on States parties to the convention. For example, states must "refrain from directly or indirectly [...] limiting the individual exercise if the right to live independently", a negative obligation, but also "reform laws that impede the exercise of the rights enshrined in article 19", a positive obligation.[21]

Since the EU accepted the CRPD in 2010, the convention forms part of EU law. 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.[22]

The core principles of independence and participation in the life of the community are also key components of Article 15 of the revised European Social Charter and Article 26 of the Charter of Fundamental Rights of the EU. In addition, the Charter of Fundamental Rights includes a cross-cutting prohibition of discrimination on the grounds of disability. The EU has a duty to comply with the Charter of Fundamental Rights in any measures affecting persons with disabilities.[23] Taken together, this provides a strong legal framework to support implementation of the right to independent living by the EU and its Member States.

At the policy level, various 'areas for action' of the European Disability Strategy 2010-2020 cover issues of independent living. In particular, the strategy commits the European Commission to support national activities to: "achieve the transition from institutional to community-based care, including use of Structural Funds".

More recently, the joint proclamation of the European Pillar of Social Rights, adopted by the EU institutions in November 2017, marks another promising policy development on the EU level.[24] Principle 17 of the Pillar refers to the 'Inclusion of people with disabilities' and affirms that "[p]eople with disabilities have the right to income support that ensures living in dignity, services that enable them to participate in the labour market and in society, and a work environment adapted to their needs." Furthermore, the Staff working document accompanying the Pillar reaffirms that the Pillar "reflects the comprehensive human rights-based approach to disability enshrined in the UNCRPD, based on respect for dignity, individual autonomy and independence of persons with disabilities, their full and effective participation and inclusion in society on equal basis with others, and equality of opportunity."[25]

In addition, most of the rights and principles in the Pillar are recognised on equal terms, regardless of any

---

[17] CRPD Committee (2018), *General comment No. 6 (2018) on equality and non-discrimination*, CRPD/C/GC/6, 9 March 2018, para. 58.

[18] CRPD Committee (2017), *General comment No. 5 (2017) on living independently and being included in the community*, CRPD/C/GC/5, 27 October 2017, para. 46.

[19] See: CRPD Committee (2017), *General comment No. 5 (2017) on living independently and being included in the community*, CRPD/C/GC/5, 27 October 2017, paras. 39-41.

[20] See: UN General Assembly (2006), *Convention on the rights of persons with disabilities*, Article 4(2). More information on progressive realisation is available in: OHCHR (2008), frequently asked questions on economic, social and cultural rights, Factsheet No. 33.

[21] CRPD Committee (2017), *General comment No. 5 (2017) on living independently and being included in the community*, CRPD/C/GC/5, 27 October 2017, para. 47.

[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] For an example of how this should be done in practice, see: European Commission (2016), *Guidance on ensuring respect for the Charter of Fundamental Rights of the European Union when implementing the European Structural and Investment Funds*, C/2016/4384, OJ C 269, 23 July 2016, p. 1-19.

[24] See: European Pillar of Social Rights.

[25] European Commission (2018), *Commission Staff Working Document accompanying the document Communication from the Commission to the European Parliament, the Council and the European Economic and Social Committee Monitoring the implementation of the European Pillar of Social Rights*, SWD(2018) 67 final, p. 77.

differentiating ground, including disability. This is the case, for example, regarding the right of "everyone" to: equal opportunities (Principle 3); adequate minimum income benefits ensuring a life in dignity at all stages of life (Principle 14); affordable, preventive and curative health care of good quality (Principle 16); long-term care (Principle 18); access to social housing or housing assistance of good quality (Principle 19); access to essential services of good quality (Principle 20).

Proclaiming all these social rights and principles on equal terms to everyone, the Pillar reaffirms the importance of people with disabilities exercising their rights, and participating in all aspects of life equally, as already enshrined in the Charter of Fundamental Rights and the CRPD.

FROM INSTITUTIONS TO COMMUNITY LIVING

FRA reports on Article 19 of the CRPD

In October 2017, the agency published three reports looking at different aspects of law and policy on deinstitutionalisation and independent living for persons with disabilities:

- **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:** 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.

These reports are also available in easy read and a summary of the reports is available in English, Bulgarian, Finnish, Italian and Slovakian.

In addition, FRA published a summary overview of types and characteristics of institutional and community-based services for persons with disabilities in the 28 EU Member States.

Why this report?

FRA wanted to contribute to making steps to implement deinstitutionalisation more effective by capturing concrete evidence of what is and what is not working on the ground. To do this, the agency conducted extensive fieldwork research in five EU Member States (Bulgaria, Finland, Ireland, Italy and Slovakia) at different stages of the deinstitutionalisation process. The fieldwork aimed to give actors involved in the deinstitutionalisation process – from national policymakers, to persons with disabilities, and the staff of institutional and community-based services – the opportunity to share their knowledge, experiences and perceptions of what drives the process forward, and the barriers that hold it back. Annex 1 gives an overview of the key drivers and barriers emerging from the research. Annex 2 presents more information on the research methodology and criteria for selecting the five Member States.

This report presents the main findings of that fieldwork. In particular, it looks at:

- **Context of deinstitutionalisation**: what are the legal and policy frameworks governing deinstitutionalisation, and how is it organised and funded?
- **Common understanding of what deinstitutionalisation and independent living mean**: what do policymakers and practitioners understand by the key terms and concepts in the area, and how does deinstitutionalisation affect those involved?
- **Essential features of deinstitutionalisation**: what are the core components of successful deinstitutionalisation processes, and how do specific drivers and barriers push the process forward or prevent it from progressing?
- **Measures to achieve successful deinstitutionalisation**: what needs to be done to make deinstitutionalisation successful?

The report does not aim to compare the deinstitutionalisation processes underway in the five Member States, but to identify common experiences of what works and what does not work in implementing successful deinstitutionalisation. It highlights the different perspectives of the wide range of stakeholders involved in deinstitutionalisation. These include those directly concerned – people with disabilities and their families; those responsible for planning and implementing the transition – national and local policymakers and staff and managers of institutions and community-based services; as well as key actors – such as DPOs and NGOs as well as members of local communities.

In this sense, the evidence presented in this report is relevant across the EU and to the wide range of different actors involved in designing and implementing institutionalisation. For example, it can support the European Commission to improve technical assistance to Member States on how to use European Structural and Investment Funds more effectively. At the national level, it indicates how national authorities can better support regional and local authorities to implement deinstitutionalisation. It also provides local stakeholders with a wealth of concrete suggestions about how to achieve deinstitutionalisation in practice. Many of the findings are relevant beyond the specific issue of deinstitutionalisation, as they concern ways to increase the independence and inclusion of persons with disabilities irrespective of whether they live inside or outside of institutional settings.

The results of the fieldwork in each of the countries are presented in the five national case studies that accompany this report.[26]

Reality check?
Local-level research on drivers of and barriers to deinstitutionalisation

FRA's fieldwork focused on implementation of deinstitutionalisation at the local level, an area little covered by previous research. The fieldwork was conducted by FRA's in-country research network, FRANET,[1] in five EU Member States that are at different stages of the deinstitutionalisation process. It was divided into two parts:

- In 2016, interviews and focus groups were conducted in each Member State with various stakeholders from the national and local level (municipalities or cities). The findings led to the identification of one case study locality in each Member State.
- In the first half of 2017, interviews and focus groups took place with a range of stakeholders in the selected case study locality.

The in-depth fieldwork research was followed by an online survey, which aimed to complement the evidence gathered from the interviews and focus groups. In the beginning of 2018, national-level peer review meetings were conducted in each of the Member States to discuss and verify the national findings.

This report incorporates findings from both parts of the fieldwork, as well as the online survey. It presents the perspectives of the different stakeholder groups that participated in the research:

- National level policymakers and experts
- Local level policymakers
- Managers and employees of institutional and community-based services
- Employees of other services e.g. health, employment, housing
- Persons with disabilities
- Family members of persons with disabilities
- National and local disabled persons organisations
- Members of local communities

Particular attention focused on ensuring that persons with disabilities were active participants at all stages of the research, reflecting the principle of 'nothing about us, without us' encapsulated in Article 4(3) of the CRPD.

In addition, careful steps were taken to ensure the anonymity of research participants. The report does not name the localities where much of the fieldwork took place, as this could lead to the identification of individual participants. The names of the persons with disabilities telling their personal stories of deinstitutionalisation are pseudonyms.

The quotes in this report were translated into English from the respective national language. They have been edited by FRA for clarity and length.

More information on the research methodology is available in Annex 2.

---

[26] These are available on FRA's website.

[27] For more information, see FRA's webpage on FRANET.

1

Context of deinstitutionalisation

The five Member States covered by this research are each at different stages of the deinstitutionalisation process. They each have different organisational structures and social welfare systems, as well as different laws and policies concerning independent living. This variety results in diverse approaches to how to achieve the transition to living in the community. Despite these differences, the research revealed high levels of awareness of and debate around deinstitutionalisation and independent living among the different groups of stakeholders concerned.

This section outlines the status of deinstitutionalisation in each of the five Member States and explores the national and local policy frameworks and funding structures in the area.

Key findings

- Significant gaps persist between policy commitments to deinstitutionalisation and progress towards achieving it in practice. Participants attributed this to a lack of effective consultation with relevant stakeholders, absence of clear timelines, insufficient funding and lack of adequate monitoring of national strategies.
- Division of competences across different levels of government has a major impact on how deinstitutionalisation is implemented. However, there is no consensus on whether centralised or devolved approaches are more effective.
    - o Strong regional autonomy can be a barrier to effective deinstitutionalisation if individual regions are not willing or able to implement it. It can also lead to disparities in progress in implementing deinstitutionalisation across different areas of a country.
    - o However, greater flexibility can enable local authorities to provide the specific services required in their area.
- Funding is a key area of concern, both in terms of the level of funding, and how it is accessed and assigned.

1.1. Status of deinstitutionalisation in the five Member States

Each of the five Member States included in this research is at a different stage in the deinstitutionalisation process. In Slovakia and Bulgaria, significant numbers of persons with disabilities remain in institutions. Very few adults living in institutions have moved to live in the community. In Finland, Ireland and Italy, deinstitutionalisation has made greater progress, with official statistics indicating that many people with disabilities in these countries have made the transition from institutional to community-based settings.[28] Participants in the research across the five countries were concerned that many community-based services may not actually enable independent living as set out in the CRPD. The persistence of institutional approaches in the community is a recurrent theme of the research.

Italy has the longest standing legislative commitment to deinstitutionalisation. In 1978, the Basaglia Law led to the closure of asylums and psychiatric hospitals, and affirmed the principles of deinstitutionalisation for people living in these hospitals.[29] These were primarily people with psychosocial disabilities, but also some people with intellectual or physical disabilities. Law No. 122 of 22 June 2016, which specifically concerns the provision of assistance to persons with severe disabilities deprived of family support, gave deinstitutionalisation a new impetus.[30] The law aims to foster the well-being, full inclusion and autonomy of persons with severe disabilities deprived of family support, as well as to prevent any institutionalisation. Among others, the law earmarks funds to support individual deinstitutionalisation processes, develop innovative residential solutions such as co-housing, and increase people’s levels of autonomy. Starting in 2018, the annual budget of this fund is € 56.1 million.

Policy has made significant strides towards independent living for persons with disabilities in Ireland and Finland, with both committing to completely close institutions. Ireland initially envisaged a complete closure of institutions by the end of 2018. However, available figures show that 2,579 people remained in institutions at the end of 2016.

Finland has progressed more rapidly towards the goal of complete closure of institutions by 2020, with 795 people reported to be living in institutions in 2016. However, many people with disabilities moved from institutions to group homes with 15 or more residents.[31] Many research participants identified the need for a ‘second phase’ of deinstitutionalisation to fully realise the aims of independent living in the community. In both countries, those remaining in institutions are typically people with intellectual disabilities, are older and generally have more severe impairments.

The deinstitutionalisation process for adults with disabilities started only recently in Bulgaria and Slovakia, and progress towards deinstitutionalisation has been slower. In Bulgaria, the documentary *Bulgaria’s Abandoned Children*[32] provoked a major public outcry both domestically and internationally, highlighting the need for a new approach to support for persons with disabilities. The deinstitutionalisation process for children with and without disabilities began in 2010, prompting an 82 % fall in the number of children in specialised institutions between 2010 and mid-2016. Most of these children now live in residential community-based services, with their families or with foster families.[33]

Policy for the deinstitutionalisation of adults in Bulgaria was laid out in 2014, but successive changes of government delayed its implementation. A new Action Plan for the implementation of the National Strategy for Long-term Care was adopted in January 2018, after the completion of the fieldwork.[34] Data suggest that 5,356 adults with disabilities lived in institutions in September

---

[28] See, for example: Ireland, Health Service Executive (HSE) (2016), *Time to Move On Bulletin*, July 2016; Karinen, R. et al (2016), *Yksilölliseen ja monimuotoiseen asumiseen. Kehitysvammaisten asumisen ohjelman arviointi asumisratkaisujen osalta*. Ympäristöministeriön raportteja 18/2016.

[29] Italy, Law No. 180 of 13 May 1978 on Voluntary and Compulsory Healthcare Checks and Treatments (*Legge n°. 180 del 13 maggio 1978, “Accertamenti e trattamenti sanitari volontari e obbligatori”*).

[30] Italy, Law No. 122 of 22 June 2016 on Dispositions concerning the assistance to persons with severe disabilities deprived of family support (Legge n°. 112 del 22 giugno 2016, Disposizioni in materia di assistenza in favore delle persone con disabilità grave prive del sostegno famigliare*)*.

[31] Karinen, R. et al (2016), *Yksilölliseen ja monimuotoiseen asumiseen. Kehitysvammaisten asumisen ohjelman arviointi asumisratkaisujen osalta*. Ympäristöministeriön raportteja 18/2016.

[32] For more information, see this webpage on the documentary.

[33] Bulgaria, Council of Ministers (2016), *Updated plan of action for the implementation of the Vision for the deinstitutionalisation of children in Bulgaria (Актуализиран план за действие за изпълнение на националната стратегия „Визия за деинституционализацията на децата в Република България“)*, Council of Ministers decision No. 859, 13 October 2016.

[34] Bulgaria, Council of Ministers (2018), Action Plan for the period 2018–2021 for the implementation pf the National Strategy for Long-term Care (План за действие за периода 2018-2021 г. за изпълнение на Националната стратегия за дългосрочна грижа), Council Decision 28 of 19 January 2018.

2017.[35] The greatest number of these are adults with intellectual disabilities, but significant numbers also live in institutions for people with physical and sensory disabilities and in mental health institutions. Very few deinstitutionalisation projects for adults are in place.

Slovakia instigated deinstitutionalisation policy following the publication in 2009 of a report on the use of EU funds to maintain large institutions, drafted by the then EU Commissioner for Economic and Social Affairs.[36] This led to the European Commission freezing the use of European Structural and Investment Funds (ESIF) for institutions in Slovakia, and prompted a number of legislative and policy commitments towards deinstitutionalisation.

Between 2013 and 2015, a pilot National Deinstitutionalisation Project was implemented in 10 institutions in Slovakia. It incorporated staff training and the development of deinstitutionalisation plans, but did

Where did the research take place? Choosing the countries and localities

The five Member States where the research took place were carefully chosen by FRA to reflect the variety in design and implementation of deinstitutionalisation in the EU. Within each Member State, FRA selected one 'case study' locality for in-depth research. This approach allowed FRA to examine different perspectives on the drivers of and barriers to deinstitutionalisation in one particular area, through interviews and focus groups with a wide range of stakeholders. FRA does not identify the localities to protect the anonymity of research participants.

In each case, the chosen locality had both institutional settings, and community-based services where some users formerly lived in institutions. All but one (Bulgaria) of the case study localities are more advanced in implementing deinstitutionalisation than the country overall. The case study localities reflect a range of socio-economic settings. In Bulgaria, for example, the local-level research took place in one of the largest cities; in Italy and Finland, in a medium sized city; and in Slovakia and Ireland, in small rural towns.

- In Bulgaria, the case study locality is a large city. There are two institutions operating at full capacity, both with long waiting lists. The community-based services in the city were developed during the deinstitutionalisation process for children, and are at full capacity with children and young adults. There is a lack of community-based services for adults with disabilities.
- Most users have left the institution in the Finnish locality; those remaining mostly have severe or multiple impairments. Persons with disabilities living in the community tend to live together, either in group homes, in their own apartments in clusters of service users, or in apartment buildings where persons with and without disabilities live in intentional communities.
- The case study locality in Italy is further ahead in the deinstitutionalisation process than is typical of the country. The locality provides various forms of in-home support to foster autonomy and hosts several day care centres, as well as a number of labour inclusion services for persons with disabilities. These facilities and services tend to be run by social cooperatives that work closely with local authorities, often also in cooperation with institutions committed to achieving deinstitutionalisation.
- In the Irish case study locality, people who have transitioned now live in dispersed housing in the community, most frequently in groups of two or three, but sometimes alone with the appropriate level of staff support. Few residents remain in the institution; among those that do, most are older and/or have severe impairments.
- The institution in the Slovak case study locality is taking the first steps towards deinstitutionalisation, and funds one supported living apartment for six people.

More information on the selection of the countries and case study localities is available in Annex 2.

---

[35] Bulgaria, Council of Ministers (2018), Action Plan for the period 2018–2021 for the implementation pf the National Strategy for Long-term Care (План за действие за периода 2018-2021 г. за изпълнение на Националната стратегия за дългосрочна грижа), Council Decision 28 of 19 January 2018, pp. 4-5. This includes 2,083 people in institutions for intellectual disabilities; 1,028 in mental health institutions; 1,287 in institutions for persons with physical disabilities, 113 in institutions for persons with sensory disabilities and 825 in institutions for people with dementia. These figures refer to the capacity of the institutions, but the report also provides numbers of people on waiting lists, suggesting that they are at full capacity.

[36] Špidla, V. (2009), *Report of the Ad Hoc Expert Group on the Transition from Institutional to Community-based Care*, Brussels, European Commission.

not result in many people with disabilities leaving institutions.[37] A second National Action Plan, adopted in September 2016, envisaging the extension of the pilot to a much larger number of institutions. The extended project had not been launched by the time the fieldwork research by FRA for this project took place.[38]

1.2. Legal and policy framework for deinstitutionalisation

"On paper, we have gone quite far because we have the deinstitutionalisation strategy, which is sometimes cited as an example of good practice, […] we have defined national priorities, […] we have several first signs in the law [of improvement, for instance provisions] that prevent the registration of new homes of social services. […] However, we are lagging behind terribly in terms of implementation. [We have a long way to go in terms of] changing the system of evaluating dependence, financing social services and introducing active support." (Slovakia, representative of an NGO)

The five Member States have committed to make the transition from institutional to community-based support for persons with disabilities in different ways. The research explored the legal and policy frameworks in each country, and asked participants to reflect on their strengths and weaknesses.[39] The difficulty of translating policy into reality emerged as a recurrent theme, experienced by different participants in different ways. Some highlighted challenges with ensuring the involvement of all relevant actors, and effective cooperation between them (as explored in more detail in Section 3.3). Others felt that the policies themselves did not reflect the situation on the ground, or were overly burdensome to implement.

"I think there is also a problem with legislation […] our laws usually have very rich and wordy premises, but in practice they remain extremely bureaucratic." (Italy, manager of a community-based service)

National legal and policy frameworks for deinstitutionalisation

At the national level, three elements came to the fore:

- role of the CRPD;
- national legislation;
- national policy.

Participants, particularly national-level stakeholders, underlined the importance of the CRPD, and in particular the right to independent living it sets out. This reflects previous FRA evidence showing that ratification of the convention helps to drive wide-ranging legal and policy reforms.[40]

Participants in Italy, for example, noted that the ratification of the convention in 2009 promoted the involvement of people with disabilities and prompted the implementation of new legislative measures to meet the convention's requirement. This included to the establishment of the National Observatory on the Conditions of People with Disabilities, as the national monitoring body required under Article 33(2) of the convention.[41] In both Finland and Ireland, where ratification occurred during (Finland) or after (Ireland) the completion of this research, participants hoped that the ratification of the convention would result in a more rights-based approach to disability and deinstitutionalisation.

However, participants in all research countries emphasised the difficulty of ensuring that the rights-based approach to disability set out in the CRPD is understood, embraced and adopted by all, including frontline staff, local communities, and persons with disabilities and their families.

---

[37] Slovakia, Implementation Agency of the Ministry of Labour, Social Affairs and Family of the Slovak Republic (2018), *Národný projekt Podpora deinštitucionalizácie a transformácie systému sociálnych služieb*.

[38] For more information about the deinstitutionalisation process in Slovakia, see: M. Cangár and M. Machajdíková (2018), *From institutional to community-based care – the case of Slovakia*, Social Reform Foundation (SOCIA).

[39] For more information, see: FRA (2017), *From institutions to community living – Part 1: commitments and structures*, Luxembourg, Publications Office.

[40] FRA (2015), *Implementing the UN CRPD: An overview of legal reforms in EU Member States*, Luxembourg, Publications Office. See also FRA's annual Fundamental Rights Reports.

[41] Italy, Law no. 18 of 3 March 2009, Ratification and execution of the United Nations Convention on the Rights of Persons with Disabilities, with the Optional Protocol, done at New York on 13 December 2006, and establishment of National Observatory on the Conditions of People with Disabilities (Legge n°. 18 del 3 marzo 2009, Ratifica ed esecuzione della Convenzione delle Nazioni Unite sui diritti delle persone con disabilità, con Protocollo opzionale, fatta a New York il 13 dicembre 2006 e istituzione dell'Osservatorio nazionale sulla condizione delle persone con disabilità).

Turning to national legislation, Slovakia[42] and Italy[43] have domestic legal guarantees specifically related to the transition to independent living. As noted, in Italy, Law No. 122 of 22 June 2016 seeks to guarantee independence and autonomy to persons with severe disabilities, avoiding an approach to support that is based on traditional healthcare assistance. The law aims to allow people to live in their own homes or in residential services managed by associations, limiting the size of these services to a maximum of 10 persons with disabilities.[44]

In contrast, all five Member States have some form of national policy on deinstitutionalisation (see Table 2). This is either a dedicated strategy for deinstitutionalisation, or relevant measures in a broader disability strategy. The CRPD Committee consistently underlines the importance of adopting deinstitutionalisation strategies.[45] Building on the CRPD Committee's guidance, FRA's 2017 report *From institutions to community living* calls on EU Member States to adopt strategies that:[46]

- are evidence-based;
- are inclusive of people with disabilities and their representative organisations;
- cover all sectors involved in the transition, including health, employment, housing and support;
- set specific targets with clear deadlines;
- are regularly reviewed;
- are sufficiently funded (this is covered in Section 1.4).

These elements provide a framework for analysing the strengths and weaknesses of the national legal and policy frameworks, as identified by research participants.

Creating an evidence-based national strategy requires reliable and accurate data. However, comprehensive and comparable data are lacking in many Member States, as FRA evidence consistently shows.[47] For example, participants highlighted that official data on numbers of persons with disabilities living in institutions

Table 2: Strategies concerning deinstitutionalisation in the five Member States

EU MS	Strategy or action plan on deinstitutionalisation
BG	National Strategy for Long-Term Care *(Национална стратегия за дългосрочна грижа)* and Draft National Action Plan for the period 2018-2021 for the implementation of the National Long-Term Care Strategy *(Проект на План за действие за периода 2018-2021 г. за изпълнение на Националната стратегия за дългосрочна грижа)*
FI	Government Resolution on Securing Individual Housing for Persons with Intellectual Disabilities 2010-2015 *(Kehitysvammaisten asumisohjelmalla linjattu vuosille 2010–2015)*
IE	Time to Move On from Congregated Settings: A Strategy for Community Inclusion (2011)
IT	Second Biannual Action Plan for the Promotion of the Rights and the Integration of People with Disabilities, 2014-2016 *(Secondo programma di azione biennale per la promozione dei diritti e l'integrazione delle persone con disabilità 2014-2016)*
SK	Strategy of Deinstitutionalisation of the System of Social Services and Substitute Care in the Slovak Republic (*Stratégia deinštitucionalizácie systému sociálnych služieb a náhradnej starostlivosti v Slovenskej republike*) and National Action Plan for Transition from Institutional to Community-based Care in the Social Services System for 2016 – 2020 *(Národný akčný plán prechodu z inštitucionálnej na komunitnú starostlivosť v systéme sociálnych služieb na roky 2016 – 2020)*

Source: FRA, 2018

---

[42] Slovakia, Act No. 448/2008 on Social Services, as amended (*Zákon č. 448/2008 Z. z. o sociálnych službách v znení neskorších predpisov*), Article 61 (6), 1 January 2014.

[43] Italy, Law no. 112 of 22 June 2016, Provisions on assistance for persons with severe disabilities and without family support (Legge n°. 112 del 22 giugno 2016, Disposizioni in materia di assistenza in favore delle persone con disabilità grave prive del sostegno famigliare).

[44] Italy, Law no. 112 of 22 June 2016, Provisions on assistance for persons with severe disabilities and without family support (Legge n°. 112 del 22 giugno 2016, Disposizioni in materia di assistenza in favore delle persone con disabilità grave prive del sostegno famigliare).

[45] CRPD Committee (2017), *General comment No. 5 (2017) on living independently and being included in the community*, CRPD/C/GC/5, 27 October 2017, para. 38 (c). See also the Committee's concluding observations on Austria (CRPD/C/AUT/CO/1) and Hungary (CRPD/C/HUN/CO/1).

[46] FRA (2017), *From institutions to community living: Part I: commitments and structures*, Luxembourg, Publications Office.

[47] FRA (2017), *From institutions to community living: Part III: outcomes for persons with disabilities*, Luxembourg, Publications Office.

may not include other types of institutional settings where persons with disabilities live, including prisons and psychiatric hospitals. In addition, the different definitions of institutions and community-based services used by the Member States mean the data are not comparable.

A gap emerged between the perception of national-level stakeholders and local level actors, disabled persons organisations (DPOS) and family members about the inclusiveness of deinstitutionalisation strategies. In Bulgaria, for example, national level authorities felt that all relevant stakeholders take part in national policy design, but this view was not generally shared at the local level. Local level participants pointed to the requirement for policy working groups to be 'nationally representative' which, they felt, excludes the perspective of independent and local-level stakeholders.

Few national strategies adequately address all the sectors involved in the deinstitutionalisation process, in the participants' view. In Italy, however, the second National Plan for the promotion of the rights and integration of persons with disabilities sets out action points that relate specifically to policies, services and organisational models to support independent living and inclusion in the community. Participants in the fieldwork in Italy felt that adding these action points strengthens the country's commitment to independent living.

The second national plan was finalised on the basis of an evaluation of the implementation of the first plan, which involved governmental representatives, DPOs, civil society organisations and experts in the area of disability, under the responsibility of the National Observatory on Disability. In addition, the action points on independent living included in the national plan specifically addresses these different groups of stakeholders.

Participants underlined the critical importance of setting specific targets with clear deadlines. In Finland, which has committed to close remaining institutions by 2020, a representative of the monitoring mechanism for the CRPD reported that this is "reasonably well on schedule. In 2020, we should have finished [the] deinstitutionalisation [process], at least that's what it says in the documents". However, participants noted that targets are not always met. In Ireland, the aim of completing deinstitutionalisation by the end of 2018 was revised in 2016 to the longer-term objective of "reduc[ing] this figure by at least one-third by 2021 and to ultimately eliminate all congregated settings".[48]

Setting specific targets is closely tied to regular monitoring and review. In Slovakia, participants highlighted that the lack of measurable goals in national policy prevents effective evaluation of progress. More generally, as States Parties to the CRPD, all EU Member States have an obligation to establish frameworks to promote, protect and monitor the implementation of the convention. Participants in Ireland, which ratified the convention in March 2018, were hopeful that the creation of a monitoring mechanism would help to hold the government accountable for targets and commitments.

Local legal and policy frameworks for deinstitutionalisation

Each of the five Member States has devolved responsibility for legislation and policy on deinstitutionalisation in different ways. Ireland has the most centralised approach, and Italy and Slovakia the most decentralised. Nevertheless, the importance of regional and local frameworks for implementation was highlighted in all countries. Throughout the research, participants pointed to disparities in the way the transition to community living is devised and implemented in different parts of the country. They also noted discrepancies in the speed and success with which the transition is progressing. However, the impact of regionalisation of deinstitutionalisation policy on achieving the transition to community-based support varied across the five countries.

In Slovakia and Italy, for example, where regional and local authorities play a key role, participants identified decentralisation as a barrier to implementing national policy uniformly across the country. For instance, the distribution of competences at four levels of governance in Italy (municipalities, provinces, regions, State) leads to different degrees of commitment to deinstitutionalisation among public authorities at the regional and the local levels. This, in turn, leads to different levels of investment in terms of budgetary and staff allocations to support deinstitutionalisation.

In Slovakia, the self-governing regions are not directly subordinate to central government. As such, successful implementation of deinstitutionalisation is closely linked to regional commitment, despite the strong national and legal policy framework.

---

[48] Government of Ireland (2016), *A Programme for Partnership Government*, May 2016, p. 72.

> *"[R]egional self-governments are not expected to go for [the deinstitutionalisation process]; in other words, if all regional self-governments in Slovakia said they refused to tackle it, nothing would happen. The money will simply not be spent on [deinstitutionalisation]; [it] will be spent on other things."* (Slovakia, regional policymaker)

Some participants in Bulgaria questioned how much policy is decentralised in practice. Although national authorities sought to encourage diversity in the provision of community-based services by decentralising them, participants at the local level felt that this decentralisation was only nominal.

> *"Formally, if you look at the law, it is not centralised because of the municipal councils and so on. However, most of the social services are made possible via [...] activities delegated by the state, or if they open a service locally the local authority tries to open it in such a way that it can be funded by the state. What else can they do? There is no funding, they cannot fund this. That is why I say that it is mega-centralised."* (Bulgaria, representative of a national disabled persons' organisation)

However, decentralisation does not necessarily result in uneven progress across different regions, according to participants. In Finland, municipalities are not directly bound by the national strategy on deinstitutionalisation, but participants did not see this as a significant challenge in terms of implementation. They highlighted two contributory factors. Firstly, the housing programme for people with intellectual and developmental disabilities *(Kehitysvammaisten asumisohjelma)* made specific funding available in addition to the budgets of the municipalities, which generally fund institutional and community-based services. Secondly, as one representative of a non-governmental organisation noted, both the relevant ministry and the Association of Finnish Local and Regional Authorities efficiently communicated the targets of the national programme to the municipalities.

In contrast, Ireland, which has a more centralised system, subcontracts many of its services for people with disabilities to voluntary service providers. Participants felt that this led to disparities in service provision as well as in the commitment and approach to deinstitutionalisation.

1.3. Organisation of deinstitutionalisation

Reflecting the different models of provision of social services in the five Member States, the distribution of responsibility between local and regional actors varies (see Table 3). Typically, the relevant national ministry sets overall policy in deinstitutionalisation, with local authorities then responsible for implementing

Table 3: Overview of governmental responsibility for implementing deinstitutionalisation, by EU Member State

EU MS	Responsibility for implementing deinstitutionalisation
BG	**National:** the Ministry for Labour and Social Affairs and its Social Assistance Agency are responsible for opening, closing and monitoring institutions and community-based services, and for funding municipal social care strategies. **Local:** Both districts and their component municipalities are expected to draft strategies for social care and plan community-based services. Funding for such services is centralised.
FI	**National:** the Ministry of Health and Social Affairs is responsible for administering the national policy on deinstitutionalisation. **Local:** Municipalities play the most important role in implementing and funding the transition to community living. However, reforms to the social and health care system coming into force in 2020 will see the regions (*maakunta*) take on responsibility for disability services for the municipalities in their region.
IE	**National**: The Health Service Executive (HSE), under the Department of Health, is responsible for setting policy and targets on the transition to community living. **Local:** The HSE has nine regional branches, which are responsible for implementation of deinstitutionalisation in their area. However, service providers are often large voluntary organisations, who have a certain degree of independence.
IT	**National:** The Ministry of Health and the Ministry of Labour and Social Policies share responsibility for deinstitutionalisation, playing a monitoring and coordination role. **Local:** Municipalities are responsible for the organisation of social services, although they often delegate authority to other intermediate authorities. Many services relevant to deinstitutionalisation are provided through social cooperatives, after a public tendering processes.
SK	**National**: The Ministry of Labour, Social Affairs and Family is responsible for the deinstitutionalisation process overall. **Local**: Slovakia is divided into eight self-governing regions which are each expected to pursue their own strategies for social services. Not all self-governing regions have addressed deinstitutionalisation in their strategies for social care.

Source: FRA, 2018

it. However, in Bulgaria and Slovakia, regional or local authorities also develop their own strategies. Cooperation between these and other actors in the deinstitutionalisation process is explored in Section 3.3.

1.4. Funding for the deinstitutionalisation process

FRA's report *From institutions to community living – part 2: funding and budgeting* highlights the complex funding picture in the EU for deinstitutionalisation. This involves a mix of different public authorities, various sources of funding and an array of service providers. This reflects the number of different public services involved in implementing the transition to independent living, and the fundamental shift in funding services for persons with disabilities required to achieve it.

Concerns about the inadequacy, inaccessibility or poor allocation of funds for deinstitutionalisation emerged in all five Member States. These issues are discussed further in Section 3.1.5.

European Structural and Investment Funds (ESIF) are the most important source of funding for the transition to community-based living in Slovakia and Bulgaria.[49] Participants underlined the crucial role of ESIF in their deinstitutionalisation processes. In Slovakia, participants noted that 10 institutions drew on the European Social Fund (ESF) to fund training during the country's deinstitutionalisation pilot project. However, European Regional Development Fund (ERDF) monies to enable the physical transition to community-based services were not forthcoming simultaneously as envisaged. In addition, there were difficulties with coordination, as the funds are administered by two different ministries. While these funds are now available, problems with coordination between ESF and ERDF funds persist. The new National Action Plan for Transition from Institutional to Community-based Care in the Social Services System for 2016-2020, which would extend the pilot project to many more institutions, is on hold at the time of writing, partly due to co-financing issues.

Supporting deinstitutionalisation through European Structural and Investment Funds (ESIF)

ESIF are the EU's main financial instruments for investing in job creation and a sustainable and healthy European economy and environment. They account for over half of the EU budget and run for seven years at a time. The current funding period ends in 2020; the next EU budget for the 2021-2027 period is under negotiation at the time of writing.

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

In 2013, the EU took a major step towards supporting deinstitutionalisation by introducing in the ESIF regulation particular conditions that must be fulfilled before funds can be spent (so-called *ex-ante conditionalities*). This has contributed to providing additional financial resources for deinstitutionalisation, particularly in the 12 EU Member States where the European Commission identified a need for measures for the shift from institutional to community-based 'care'. Much more information on the role of ESIF in supporting deinstitutionalisation is available in FRA's report *From institutions to community living- Part II: funding and budgeting,* published in 2017.

---

[49] For detailed analysis of the use of ESIF in the context of deinstitutionalisation and independent living see: OHCHR 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.

However, a number of challenges remain and evidence points to misuse of EU funds to renovate or build new institutions. Reflecting concerns expressed by civil society organisations, the CRPD Committee called on the EU to “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 European Commission published its proposal for the regulation governing ESIF for the 2021-2027 period in May 2018. The proposal replaces the ex-ante conditionalities with so called ‘enabling conditions’. While fewer in number, these conditions are more focused and aligned with EU priorities and policy objectives. In addition, rather than serving as a precondition at the onset of the funding period, as was the case with the ex-ante conditionalities, they should be fulfilled and applied throughout the implementation period and monitored regularly. To support this, the Commission proposal requires Member States to establish a performance network to “allow monitoring, reporting on and evaluating programme performance during its implementation”.

The thematic enabling conditions applying to the European Social Fund+ (ESF+) and the European Regional Development Fund (ERDF) retain the specific provision on the transition from institutional to community-based ‘care’ included as an ex-ante conditionality in the 2014-2020 period. Typically, ESF is allocated to ‘soft’ investments, such as developing tools, quality assessment or training, while ERDF resources are used for funding new housing infrastructure or infrastructural development.

ESIF are also the main financial instrument supporting implementation of the European Pillar of Social Rights; implementing the pillar is a main policy objective of ERDF and ESF+. The enabling conditions under this objective specifically mention “measures for the shift from institutional to community-based care” with respect to social inclusion and poverty reduction, and “measures to promote community based services, including prevention and primary care, home-care and community-based services” with respect to health.

For more information on ESIF see EU budget for the future*. See also* European Commission’s proposal on the next funding period*, in particular Chapter II: Enabling conditions and performance framework, and Annex IV: Thematic enabling conditions applicable to ERDF, ESF+ and the Cohesion Fund.*

** 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.*

*** CRPD Committee (2015),* Concluding observations on the initial report of the European Union*, CRPD/C/EU/CO/1, 2 October 2015, para. 50.*

In Bulgaria, participants emphasised the vital role of ESIF in achieving deinstitutionalisation of children, and hoped they would play the same role in the transition of adults.

“If it was not for the support of [ESIF], even a large municipality would not have any success in developing social services and in deinstitutionalisation. […] So I would strongly emphasise the enormous help of [both funds] […]. [I]f it was not for this financial support I am almost sure that it would not happen.” (Bulgaria, local policymaker)

Despite their crucial role, participants in Bulgaria and Slovakia reported specific challenges associated with using ESIF to support deinstitutionalisation. Many spoke about gaps in funding due to the project-based financing of activities. This jeopardises the continuity and sustainability of services created and financed by ESIF (see Section 3.1.5). In addition, NGO and DPO participants highlighted what they saw as unequal access to ESIF funding. NGOs sometimes cannot apply for funding in the same way as municipalities, although they are often recognised as developing and implementing innovative practices. The result is that these organisations often need to fit their innovative ideas into the (sometimes) limited parameters of state-funded services to obtain sustainable funding.

Deinstitutionalisation is funded through national, regional or local funds, or a mix of all three in Finland, Ireland and Italy. This funding is often tied to particular pieces of legislation or policy. In Finland, social services are funded through municipalities. In addition to municipal tax revenues, municipalities receive state subsidies so that all citizens can access a certain level of basic services. The housing programme for people with intellectual and developmental disabilities also provided additional national funding for housing for persons with disabilities.[50] Participants identified this as crucial for driving deinstitutionalisation forward.

In Italy, Law No. 122 of 26 June 2016 provides for specific assistance for people with severe disabilities who do not have family support, including the creation of innovative housing solutions. In addition, a wide range of national funds, some directed towards specific impairments and some for specific purposes, fund different aspects of deinstitutionalisation. As highlighted in the following quote excerpt, one official voiced support for this approach.

---

[50] Finland, Housing Programme for Persons with Intellectual and Developmental Disabilities 2010-2015 (Kehitysvammaisten asumisohjelma).

"That's the way it should be, because the mosaic is very complex. [...]. Taken together, all these [funding] components certainly contribute to supporting measures to foster [deinstitutionalisation]." (Italy, national policymaker)

These national funds are supplemented by regional funding. For example, Tuscany has allocated € 9 million every year since 2014 for independent living projects.

The financial crisis played a part in the lack of additional resources allocated for implementation of the *Time to move on* strategy in Ireland when it was adopted in 2011. Earmarked funds for deinstitutionalisation were put in place in 2016, including capital investment to provide new housing for people leaving institutions and a Service Reform Fund to support the implementation of reforms.

2

Common understanding of what deinstitutionalisation and independent living mean

> *"Living independently and being included in the community […] means exercising freedom of choice and control over decisions affecting one's life with the maximum level of self-determination and interdependence within society."*
>
> *CRPD Committee (2017), General comment No. 5 (2017) on living independently and being included in the community, CRPD/C/GC/5, 27 October 2017, para. 8*

The terms deinstitutionalisation and independent living mean different things to different people. Studies show that very varied processes with a wide range of goals are described as deinstitutionalisation to achieve the aim of independent living.[51] What is not in doubt for participants in this research, however, is the positive impact of deinstitutionalisation on those involved, most significantly persons with disabilities.

The lack of a common understanding of these concepts has, however, a significant impact on how the right to live independently is implemented in practice, as processes with different goals and put in place in different ways are likely to have different outcomes. The CRPD Committee has underlined its concern that the misappropriation of key terms itself represents a major barrier to the implementation of deinstitutionalisation and achievement of independent living in the spirit of Article 19 of the convention. Its General Comment on Article 19 sets out detailed definitions of key terms, which can guide further processes of deinstitutionalisation.[52]

Recognising the importance of exploring how key actors understand these terms, all participants in the FRA research were asked what they understand by 'independent living' and 'deinstitutionalisation', as well as what differences they think exist between institutional and community-based services. This chapter analyses the views of the groups of stakeholders that participated in the fieldwork. The chapter then looks at the impact of deinstitutionalisation on those involved in the transition, particularly people with disabilities.

Key findings

- Meaningful deinstitutionalisation requires both a physical and a cultural transformation. It must entail:
  - a physical move away from institutional settings to accommodation in the community;
  - a shift in how services for persons with disabilities are provided, away from 'one size fits all' approaches towards individualised, user-controlled support in the community.
- Key terms such as 'deinstitutionalisation' and 'independent living' are frequently misunderstood. Sometimes independent living is misconstrued as meaning that persons with disabilities live in the community with limited or no financial and staff support.
- Not all actors support deinstitutionalisation for all persons with disabilities, irrespective of type or severity of impairment.
  - National level stakeholders were generally firm about the right of everyone to live independently in the community, irrespective of type or degree of impairment.
  - Some local-level participants felt that independent living is not appropriate for those with severe impairments or challenging behaviour. This is partly because of a lack of suitable community-based services for people with complex needs.
- Deinstitutionalisation has an overwhelmingly positive impact on persons with disabilities. Family members, staff and the wider community also benefit.

---

[51] Mansell, J., Knapp, M., Beadle-Brown, J. and Beecham, J. (2007), *Deinstitutionalisation and community living – outcomes and costs: report of a European Study*. Volume 2: Main Report. Canterbury: Tizard Centre, University of Kent; Ilinca, S., Leichsenring, K. and Rodrigues, R. (2015), *From care in homes to care at home: European experiences with (de) institutionalization in long-term care*, European Centre for Social Welfare Policy and Research.

[52] CRPD Committee (2017), *General comment No. 5 (2017) on living independently and being included in the community*, CRPD/C/GC/5, 27 October 2017, para. 16.

2.1. Key terms and concepts

"I am [always] thinking about how to describe [deinstitutionalisation] in one word and I guess it would be a revolution, a revolution towards humanity." (Slovakia, employee of a community-based service)

Participants were clear about the significant differences between institutional and community-based services. Nearly all were equally clear that community-based services are preferable. They characterised institutions as often physically distant from where people without disabilities live and offering little room for privacy or personalisation. Institutions were almost universally perceived as limiting the choices of individuals. In the few cases where institutions were viewed more positively, this was seen as necessary to protect persons with disabilities. Staff of institutional services and some family members in Italy, for example, felt that institutions provide safety and security from which residents might gradually explore greater independence.

"What makes the home an institution [is] not the building, but the inability to provide individual care."(Bulgaria, manager of a community-based service for people with psychosocial disabilities)

In community-based settings, in contrast, persons with disabilities enjoy greater space and privacy and more opportunities to participate actively in society. Participants recounted their experience that, in many cases, persons with disabilities found that they require much lower levels of support in the community than had been provided in the institution. This allows them to regain self-confidence, exercise self-determination and learn new skills.

"During my student days [...] we went to see [a particular] institution, I visited one ward and I [...] turned around, went outside and I leaned against a tree and cried. And I thought that, no matter how [my son] turned out, I will never put him there. [T]here were no curtains, there was nothing there, it felt dreary somehow. A lot of people in a small space, they didn't have their own rooms and such. Now there are proper apartments, 'I have my own flat, I lock the door, no-one can come in, this is my home'." (Finland, family member of a person with disabilities)

These differences underpinned a conviction that deinstitutionalisation entails fundamental changes in how and where services for persons with disabilities are provided. The majority of participants, across all countries and stakeholder groups, distinguished between the physical and cultural dimensions of deinstitutionalisation. They identified the move to community-based settings and greater personal space as key physical components. Cultural aspects include how services are provided, the extent to which persons with disabilities can exercise choice and control over their living arrangements, relationships between staff and service users, and opportunities for participation in the local community.

Figure 2: Physical and cultural characteristics of institutional settings

Physical characteristics of institutions

- large buildings
- isolated / remote locations
- segregation - only people with disabilities
- large groups of non-family members living together
- long lenght of admission / residence
- compelled to live together
- sharing room and personal space

Cultural characteristics of institutions

- lack of privacy and intimacy
- lack of liberty and expression of wishes
- lack of accountability
- strict schedule / regime and predefined procedures and activities
- block treatment defined by one size fits all; individual's lack control over daily activities
- rules and interest of the institution take precedence over the will and preference of the client
- devision between staff and users - medical model of care reducing individuals to their diagnoses/impairment
- no choice of support personel
- place of residence contingent on care provision

Source: FRA, 2018 (based on stakeholder views)

Participants in the fieldwork reflected on the interlinkages between the physical and the cultural dimension and on the importance of ensuring that deinstitutionalisation processes incorporate both. Participants involved in community-based services expressed particular concern that policymakers focus on physical elements to the exclusion of the cultural aspect.

> *"I think, unfortunately, community-based is sometimes looked at in terms of bricks and mortar, as opposed to looking at it in the context of the individual. The word community means connecting with community, living in a community."* (Ireland, representative of national Article 33(2) monitoring body)

> *"We do not just need new houses and buildings, we need a paradigm shift – the way we regard people needs to be changed. This is very important."* (Bulgaria, director of a community-based service)

A lack of attention to cultural elements can lead to the continuation of institutional approaches within supposedly deinstitutionalised services. In Finland, for example, some people with disabilities talked of strict curfews and routines, including having to switch off the lights at a specified time in community-based services. This problem of 'mini-institutions' – where institutional practices persist in community-based settings – was identified in all five countries. Participants considered ingrained staff culture (discussed in Section 3.2.4) and inflexible rules and regulations (discussed in Section 3.5.5) as potential reasons for the persistence of institutional approaches.

Two other ways in which the failure to address physical and cultural aspects of deinstitutionalisation prevents its full realisation emerged during the course of the fieldwork. First, as noted by an NGO participant from Slovakia, deinstitutionalisation often incorporates discussions about 'humanising' social services to focus more on the user. However, this does not always result in meaningful changes in the way social services are provided. Second, many persons with disabilities living in the community continue to attend segregated day services, limiting the opportunities for integration into the community. This also reflects a lack of employment opportunities for persons with disabilities (discussed in Section 3.5.6).

Despite broad agreement on the overarching concepts of deinstitutionalisation and differences between institutional and community-based services, the fieldwork brought to light ongoing debates about what these concepts mean in practice. Three particular issues emerged, which link closely to parts a), b) and c) of Article 19, respectively, as illustrated by the following examples:

- **Size of community-based living arrangements:** in Ireland, the national strategy, *Time to Move On*, defines an institution as any building which houses more than 10 people, while an acceptable community-based living arrangement should house no more than four. In Finland, however, people have been 'deinstitutionalised' into group homes with 15 or more residents. The General Comment on Article 19 specifies much smaller living arrangements, stating that: "Mandatory 'package solutions' which […] expect two or more persons to live together or can only be provided within special living arrangements are not in line with Article 19."[53]
- **Availability of support in the community**: some local-level participants in Bulgaria understand independent living to mean receiving minimal or no staff support and being financially independent. NGOs and national-level public officials, however, highlighted the opportunity to live in the wider community and to be able to make decisions, including about where to live, regardless of earning power or financial circumstances.
- **Access to general services in the community**: Many participants across the five countries stressed the importance of looking beyond disability-specific services that are often provided as 'package solutions'. They highlighted the importance of enabling persons with disabilities to access services available to the general public on an equal basis.

> *"Autonomy goes beyond [disability] services, because active employment, housing, social and integration policies [are found] where one lives, not within services […] The community has to grow in terms of opportunities it can offer […] for different needs […] I think we should talk about citizenship rights: I mean, in the end, the people we support on this pathway are ultimately asking for the right to health, the right to housing, the right to work, the right to love, the right to a family, the rights to citizenship."* (Italy, employee of a community-based service)

The research also revealed that some participants felt that deinstitutionalisation was either not possible or desirable for some persons with disabilities. This runs counter to the CRPD Committee's insistence that considering personal services "too costly" or that certain persons with disabilities are "unable" to live outside institutional settings, is "contrary article 19, which extends the right to live independently and be included in the community to all persons with disabilities, regardless of their level of intellectual capacity, self-functioning or support requirements".[54]

---

[53] CRPD Committee (2017), *General comment No. 5 (2017) on living independently and being included in the community*, CRPD/C/GC/5, 27 October 2017, para. 17.

[54] CRPD Committee (2017), *General comment No. 5 (2017) on living independently and being included in the community*, CRPD/C/GC/5, 27 October 2017, para. 21.

Participants across the five countries noted a gap between rhetoric and reality concerning deinstitutionalisation for persons with severe impairments and complex needs. National-level policymakers tend to take a rights-based approach, upholding the right of all persons to live in the community, regardless of the degree or type of impairment.

Some local-level practitioners, however, felt that it is unrealistic to expect those with severe impairments to live in the community and that only institutions could provide the necessary level of support (see Section 3.6.1). Part of this hesitancy is linked to the lack of appropriate community-based services for people with complex needs. Some local practitioners who are committed to deinstitutionalisation for all argued that national-level policymakers, despite their insistence that deinstitutionalisation should be possible for all, do not allocate sufficient resources for developing relevant community-based services.

Participants also had divergent views on whether deinstitutionalisation is desirable for persons with challenging behaviour. Objections ranged from concerns that persons with disabilities could pose a danger to themselves or others, to fears of a resulting increase in stigmatisation. However, other participants noted that challenging behaviour often decreased when people were removed from the stress and lack of privacy of institutional settings. Transitioning to smaller community-based settings frequently resulted in a dramatic improvement in the lives of those with challenging behaviours, as well as those of other people who had lived in the institution with them.

Some participants also recounted instances where transition process was perceived to have 'failed' for individuals with high support needs because they were not living 'independently' in the community. This was then used by sceptics to cast doubt on deinstitutionalisation more broadly.

"[The term independent living is] like a weapon or a stick that people use [...]. You're expecting to take Johnny out [to] community and you expect Johnny to be independent and six months later, 'Sure, I told you Johnny's not independent'." (Ireland, employee of a service providing institutional and community-based services; names are pseudonyms)

2.2. Impact of deinstitutionalisation

When discussing how best to achieve deinstitutionalisation, it is vital not to lose sight of the perspectives of the people undergoing that transition. On this point, participants were categorical – all those who had undergone deinstitutionalisation felt it was a hugely positive change, as did staff, families and community members close to them. They highlighted a number of concrete benefits:

- Greater choice and control for persons with disabilities.
- More space and privacy.
- Better relations between staff and service users, and between staff.
- Newly developed skills and greater independence.
- Increased involvement in community life.

These tie in closely to the definitions of independent living, being included in the community and independent living arrangements set out in the General Comment on Article 19.[55]

Increased choice and control was perhaps the most significant positive change highlighted by persons with disabilities. This concerned both big life decisions, such as whom to live with, and daily choices, such as food and routine.

"They [their staff] help me go to town, come home, do shopping, go out and [they don't say] what time are you coming back and what time you go bed, what time you get up. Yeah, [I] move out and make more friends. And go out, come home late at eleven o'clock." (Ireland, person with a disability)

People enjoyed greater space and privacy following the transition to the community, both in relation to other service users and to monitoring by staff.

"[The biggest difference between living in an institution and living independently is] the fact that there are staff around 24/7. They are observing you, watching you. When you live alone, there are no staff around anywhere." (Finland, person with a disability)

Service users, staff and managers who have experience with deinstitutionalisation all spoke of better relationships between staff and service users and between staff themselves**.** One manager of a service providing institutional and community-based services in Ireland noted that the staff "start looking at the [service users] as being individuals" and took a more flexible approach to their work, "whereas in the congregated settings, 'It's not my job', you know".

Families also react positively to the deinstitutionalisation process. While frequently expressing initial concerns, primarily with regard to the safety and security of their relative (see Section 3.2.6), they were generally

---

[55] CRPD Committee (2017), *General comment No. 5 (2017) on living independently and being included in the community*, CRPD/C/GC/5, 27 October 2017, para. 16.

impressed by the newfound skills and abilities that their family member displayed in community settings.

"In fact one resident moved to us straight from home, 42 years old now, and [when he moved] he was a little under 40. The first thing that the father said was that it's no use teaching an old dog new tricks, he's not going to learn anything. A month went by, he was doing the laundry, putting the dishes into the dishwasher, hoovering, helping to clean his room, taking out the rubbish. They came to visit him. He put the dishes into the dishwasher, the father was asking what he was doing. He's doing his household chores. They were completely shocked." (Finland, employee of a community-based service)

In some cases, family and friends became more involved in service users' lives following deinstitutionalisation. Some felt freer to visit their relative in a home-like setting, while others saw their adult children growing more independent from them, preferring to stay in their own apartment rather than visit the family home every weekend.

For those with more severe disabilities, knowing how they might respond to deinstitutionalisation is challenging. However, many stakeholders testified to greatly reduced stress levels. As one mother explains in the highlighted quote, the transition had a very positive impact on her severely autistic daughter's behaviour.

"It is a huge, fantastic change in her. She is a much happier girl now. When she was in [the institution] she had big patches, bald patches from twisting her hair out and I didn't realise that that was saying she was unhappy. I thought that was just what she did." (Ireland, family member of a person with disabilities)

Service users and their support staff also highlighted the positive benefit of increased interaction with the wider community. In Bulgaria, the deinstitutionalisation of children in the case study locality initially triggered protests from the local community. Over time, however, participants watched better relations develop between people with disabilities and their neighbours. Some neighbours pay social calls to the group homes, while others employ people with disabilities for odd jobs. This contributes to the sense of being valued members of the community, as well as increased financial independence.

Finally, participants highlighted that the deinstitutionalisation process can contribute not just to the fulfilment of rights of persons with disabilities, but also to the creation of more inclusive societies.

"I think it is not as necessary [for the sake of persons with disabilities] – of course, it is also good for them [...] but I believe it is rather about the common good, about making people come together." (Slovakia, member of the local community)

“My story is not easy to tell,” begins Adele. “I was born in 1957, I don’t know why my mother abandoned me, maybe she was poor or maybe she didn’t want me. As soon as I was born I was sent to a Catholic institution.” She described how she went from institution to institution, then to a family shelter and then back to another institution, without ever fully understanding why.

“Then one day, I was called and they told me that I could go and live in a flat and that I could choose whom to share the flat with and I discarded so many names and then I said yes and, my friend Francesca said yes, that it was fine for her too and we moved. When we saw it for the first time, the flat was empty but cool, then we chose the colour of the kitchen and I chose light blue. There was the light-blue kitchen as I wanted it to be.”

She describes her daily routine with Francesca: “We wake up in the morning. I’m always the first to wake up! ‘Francesca, it’s late, get up!’, I tell Francesca. She wakes up and goes to prepare coffee. No, she doesn’t! She comes back because she always forgets to make her bed in the morning. She makes her bed. I make mine. Then she prepares coffee. After that, we get ready: we check the lights, the water and the gas. Then we go to the bus stop and wait. We get off in Moccia. We walk to the residence and ring the bell: ‘Who is that?’ asks Franco. ‘It’s us!’ We go upstairs. We are independent at the residence.”

Adele works in the pizzeria: “I’m in charge of cleaning and doing some work in the kitchen too: I wash the salad and cut it to put it on the plates. Then at about 4.30 pm we go back. The bus brings us back home and as soon as I arrive, I immediately have a shower and I relax watching TV and then go and do some shopping if I need to or I go out and have a coffee at the cafe.”

“I like my life at the moment and I wouldn’t change it; living in a flat with Francesca is fine. I’ve learnt so many things and I like to do them!”

ADELE’S STORY — ITALY

HUMAN STORIES

3

Essential features of the deinstitutionalisation process

A great variety of drivers of and barriers to deinstitutionalisation emerged from the research. This chapter presents the main drivers and barriers, grouped according to the five key features of successful deinstitutionalisation identified by FRA. It then looks at how two important cross-cutting issues influence the deinstitutionalisation process: the type and degree of impairment, and the role of age.

The methodology implemented in the research was specifically designed to allow those most closely concerned by the process to identify the principal drivers of and barriers to the deinstitutionalisation process as they see them.

FRA has grouped these drivers and barriers into five essential features of a successful deinstitutionalisation process (see Table 4). These five features are closely interrelated and mutually reinforcing. Active cooperation can help to change attitudes, for example, while effective guidance can greatly enhance practical cooperation. Each feature is a critical component of a successful deinstitutionalisation process. Annex 1 presents an overview of the key drivers and barriers emerging from the research across the five features.

Table 4: The key features of a successful deinstitutionalisation process

Key feature	Explanation
Commitment to deinstitutionalisation	• On the part of authorities at the national, regional and/or local levels. • On the part of people involved in the process, that is, staff of services for persons with disabilities, families, persons with disabilities.
A change in attitudes towards persons with disabilities	• Towards deinstitutionalisation and how services and support are provided to persons with disabilities. • Towards empowering persons with disabilities to live independently.
Active cooperation between the people involved in deinstitutionalisation	• Between different levels of governance (national, regional, local). • Between different sectors involved in the deinstitutionalisation process (for example, health, housing, employment). • With families and persons with disabilities, the local community and disabled persons' organisations.
Availability of guidance to support deinstitutionalisation	• Tools on how to implement the deinstitutionalisation process. • Training and re-training of staff who work on the deinstitutionalisation process. • Pilot projects on deinstitutionalisation.
Practical organisation of deinstitutionalisation	• Organisation and implementation of the deinstitutionalisation process. • Availability of support services in the community. • Preparing people involved in the process for deinstitutionalisation.

Source: FRA, 2018

Many of the issues raised under each feature can act as either drivers of or barriers to the deinstitutionalisation process, depending on the context. For example, some participants in the research highlighted staff attitudes as driving the process forward, based on their experience of motivated, forward-looking staff. Others experienced staff attitudes as a barrier holding it back, citing instances where institutional habits have moved with staff from institutional settings into community-based living arrangements.

Key findings

- Commitment to deinstitutionalisation and changes in attitudes are the most crucial features for achieving deinstitutionalisation. They are closely interlinked: changing attitudes towards people with disabilities drives policy commitments, and successfully implementing policy commitments involves changing attitudes at all levels. Active cooperation, availability of guidance and practical organisation are important supporting elements for the deinstitutionalisation process.
- Stakeholders with formal responsibility for implementing deinstitutionalisation – public authorities at the national and local level, and managers and staff of institutional and community-based services – highlighted commitment as the most important feature. By contrast, those engaged in deinstitutionalisation in a more personal capacity – persons with disabilities and their families, and DPOs – identified attitudes as most important.
- Commitment at both national and local level are vital. This needs to be accompanied by adequate funding and empowerment of persons with disabilities. Criticism of continued institutionalisation can help to drive national commitment. However, deinstitutionalisation can be blocked by actors with vested interests in maintaining the status quo.
- Better public attitudes, positive images of persons with disabilities in the media and forward-looking staff help to drive deinstitutionalisation. By contrast, persistent paternalistic attitudes towards people with disabilities on the part of staff, and families' fears for the safety and security for their relatives leaving institutions, can lead them to oppose deinstitutionalisation.
- Closer cooperation between the different actors involved in the deinstitutionalisation process and with people with disabilities and local communities, are key drivers. Cooperation with civil society and third-sector organisations also supports the process. Failure to include local level actors in decision-making processes and a lack of clarity about the respective roles of different actors can undermine effective deinstitutionalisation, however.
- Guidance from national policymakers to local services, to people with disabilities transitioning to community living and their families, and to support staff help further deinstitutionalisation. Pilot projects showcasing deinstitutionalisation in practice are also important.
- Having adequate individualised support available in the community is key to organising deinstitutionalisation in practice. However, not enough such services yet exist, and general services open to the public are often inaccessible. This, combined with inflexible rules and regulations on services with disabilities and a lack of employment opportunities for persons with disabilities, restrict progress towards deinstitutionalisation.
- Persons with intellectual disabilities and those with severe impairments face the biggest barriers to deinstitutionalisation. Some participants did not support deinstitutionalisation for people with severe intellectual disabilities.
- Many participants expressed reservations about deinstitutionalisation for older people, arguing that the transition would be particularly difficult for people who have spent long periods in institutions. At the other end of the age spectrum, younger people demanding appropriate community-based services are helping to drive deinstitutionalisation.

3.1. Commitment to deinstitutionalisation

Participants across countries and stakeholder groups agreed on the crucial importance of political commitment to deinstitutionalisation. Where present, it helps to drive the deinstitutionalisation process forward; where absent, it is a factor preventing progress. FRA's report *From institutions to community living – Part 1: commitments and structures* explores the legal and policy aspects of commitment in more detail.[56]

---

[56] FRA (2017), *From institutions to community living: Part I: commitments and structures*, Luxembourg, Publications Office.

Key drivers		Key barriers
3.1.1 National political commitment to deinstitutionalisation Political commitment at the national level, backed up with adequate policies and implementation measures, is crucial for successful deinstitutionalisation.	**Commitment to deinstitutionalisation**	**3.1.5 Insufficient, difficult to access or poorly assigned funding** Insufficient, poorly spent or difficult to access funding is a recurring barrier. Some participants, however, pointed to examples of good results achieved in the absence of specific funding.
3.1.2 Commitment at local level For the process to move forward, national commitment should be complemented by commitment at the local level. Local-level commitment can serve to inform, strengthen and campaign for greater national commitment.		**3.1.6 Vested interests trying to block deinstitutionalisation** Participants spoke of instances of corruption, and reluctance on the part of providers of institutional services to change existing models.
3.1.3 External pressure to hasten deinstitutionalisation National commitment sometimes emerges in response to external pressures from the media, monitoring reports and the EU itself, particularly in relation to ESIF. However, many participants questioned if this would produce reactive results that could be of poorer quality.		**3.1.7 Deprivation of legal capacity** Deprivation of legal capacity can lead to or lengthen institutionalisation and contributes to risk aversion among staff, resulting in people being assessed as needing much higher levels of support than they actually do.
3.1.4 Persons with disabilities demanding deinstitutionalisation Empowerment of persons with disabilities is a crucial aspect of commitment to deinstitutionalisation.		

Driver 1: National political commitment to deinstitutionalisation

Participants were clear on the importance of a strong national legal and policy framework for deinstitutionalisation, but underscored that this must be backed up by adequate funding and followed through. They reflected on their experiences of the strengths and weaknesses of their national frameworks.

Finnish stakeholders were most positive about the strength of national commitment. Participants from across stakeholder groups identified commitment embodied in a strong national legal and policy framework for deinstitutionalisation, the ratification of the CRPD and direct national funding for housing in the community as paving the way for municipalities to make deinstitutionalisation a reality.

Participants elsewhere raised concerns about gaps in this commitment in practice. In Italy, participants cited Law No. 122 of 26 June 2016 as signalling a unified commitment to deinstitutionalisation, moving away from voluntary pilot projects towards a firm national commitment to close institutions and create community-based services. However, some criticised the accompanying funding as insufficient.

Participants at both national and local level in Ireland focused on what they felt to be a lack of progress in implementing the national strategy on deinstitutionalisation. One highlighted the consequences of delays for persons with disabilities living in institutions.

"What's been happening nationally to me seems to be very slow. I'm looking at it, thinking why are people just not grabbing it and going with it? Because another year will have passed […] and the people will be getting older and they're still living in institutions." (Ireland, manager of service providing institutional and community-based services)

In Slovakia and Bulgaria, national and to some extent local authorities generally felt that the necessary political will is in place. This was strongly contested by local community-based service providers, civil society and representatives of organisations for persons with disabilities, however.

"We have many words and nice looking documents but deeds/implementation is entirely absent. Therefore the term 'commitment to the [deinstitutionalisation]' is insufficient for me if strategies […] and action plans are not followed by actions." (Slovakia, representative of a disabled persons' organisation)

Representatives of Bulgarian advocacy organisations argued that deinstitutionalisation is not a political priority, but a reaction to external pressure, including meeting the requirements attached to ESIF (see Section 3.1.3).

Notably, some local-level authorities and service providers saw the national policy shift towards deinstitutionalisation as a barrier to their work. This often reflected a reticence to alter existing models of service delivery, as well as doubts about the appropriateness and desirability of deinstitutionalisation (see Section 3.1.6 and Section 2.1).

STANISLAV'S STORY — BULGARIA

HUMAN STORY

Stanislav grew up without parents – his mother died and he never knew who his father was. As a child, he went to a mainstream school in his village but fell behind. Nobody paid attention to his problems at school so he moved to a special school for people with disabilities after fourth grade. When he was about to graduate, social workers offered him the opportunity to go to a specialised vocational boarding school. He chose one closer to his hometown and moved there to study as a painter. After graduating, he was unsuccessful in his attempts to find a job. He had no home or any other support, so he went to an institution for adults with intellectual disabilities where he could have food and a roof over his head. He lived there for 15 years, from 2002 to 2016.

Stanislav was not happy there. He lived with 47 different people – young and old and with different conditions that he had to adapt to. He says that he was lucky to share a room with four more people with lower levels of impairment and therefore was not as restricted in his movements, but he felt isolated from his friends outside and was ashamed to invite them to visit, as they saw the other people in the institution and did not want to visit him anymore. He felt lonely as the other residents became gradually less capable of having a conversation. When he heard that new types of services, sheltered houses, were opening, he asked to leave the institution. He went to the director and told him that he didn't feel he belonged in the institution any more, that he didn't want to spend the rest of his life there. The director understood and helped him to move out to a protected house.

Stanislav was free to come and go from the institution so he visited the protected house and asked what he had to do to apply to live there. He prepared the documents needed himself and applied to the Social Protection Directorate. He waited a month for his application to be approved – it felt like a very long month!

He moved to the protected house in mid-2016. He likes it a lot and is happy to remain there rather than looking for a home of his own. He feels free and likes the house very much. He has skills in construction and is often employed. Now he has his own income and can afford to buy various things like a mobile phone, food he likes to eat and nice clothes. He is thankful for the chance to live there.

Driver 2: Commitment at local level

Commitment at the national level needs to be mirrored at the local level, in participants' view. Many stakeholders at the local level argued that local commitment to deinstitutionalisation in certain regions or services is actually stronger than national commitment. This may reflect the selection of the case study localities, most of which are at the forefront of deinstitutionalisation in their countries.

Participants experienced the positive impact of local commitment in different ways:

- In Finland, the case study locality began the deinstitutionalisation processes in advance of national policy. It is ahead of national policy in identifying new types of housing solutions in the community.
- Regional and local pilot projects in Ireland and Italy play an important role in informing, encouraging and developing national policy.
- In Slovakia and Bulgaria, where many participants felt that national conditions are largely unfavourable for deinstitutionalisation, the commitment of local service providers overcomes significant barriers and drives initial steps towards transition.

Promising practice

Slatinka Social Services Home

The Slatinka Social Services Home (*Domov sociálnych služieb Slatinka – DSS Slatinka*) in **Slovakia** initiated the first moves towards community living in 2008, ahead of any national commitments. Participants attributed this to the dedication of management and staff.

In 2013, DSS Slatinka joined the national deinstitutionalisation project and received leadership support and training funded by the European Social Fund.* However, in common with the other pilot projects, planned funding for the physical transformation never materialised. In this case, the regional governor blocked the funds.

Despite the lack of ESF funding, the home funded deinstitutionalisation through its general budget from the self-governing region and grant money from various projects. By 2017, DSS Slatinka included more than eight supported living flats.** The Home's clients, previously assessed as highly dependent on care, developed their independent living skills significantly following relocation. Many now live with little support. They are active in campaigning for the rights of other persons with disabilities in Slovakia. During the review of Slovakia's progress in implementing the CRPD in 2016, Slatinka clients told the CRPD Committee about the impact of the transition process on their lives.***

* Slovakia, Implementation Agency of the Ministry of Labour, Social Affairs and Family, Basic information (*Základné informácie*).

** Brichtová, L., Filipová, M., Končeková, D., Kopcová, E., Samová, M. (2015), *Záverečná hodnotiaca správa. Národný projekt Podpora deinštitucionalizácie a transformácie systému sociálnych služieb*, Bratislava, Implementation Agency of the Ministry of Labour, Social Affairs and Family, p. 128. For other information on the deinstitutionalisation process in Slatinka, see Holúbková, S., and Ďurana, R. (2013), *Odvaha na nové služby*, Bratislava, INESS, p. 28, or SOCIA (2015), Simple happiness (video with English subtitles).

*** Documents relating to the review of Slovakia are available on the CRPD Committee's website.

Driver 3: External pressure to hasten deinstitutionalisation

Many participants pointed to the role of external pressure of different kinds in creating or reinforcing national political will and momentum where these are lacking.

Following concerns that ESIF had been spent on renovating existing institutions or building new institutions, the EU introduced safeguards to ensure the funds support deinstitutionalisation and made deinstitutionalisation an investment priority in 12 EU Member States for the 2014-2020 funding period (see Section 1.4).[57] Participants in both Bulgaria and Slovakia credited these steps with prompting greater political focus on and commitment to deinstitutionalisation. External pressure in Bulgaria also came in the form of key judgments from the European Court of Human Rights, namely the *Stanev v. Bulgaria* and *Stankov v. Bulgaria* cases.[58] Both cases, brought by European civil society organisations, concern clients deprived of legal capacity

---

[57] FRA (2017), *From institutions to community living- Part II: funding and budgeting*, Luxembourg, Publications Office.

[58] European Court of Human Rights (ECtHR), *Stanev v. Bulgaria*, No. 36760/06, 17 January 2012 and ECtHR, *Stankov v. Bulgaria*, No. 25820/07, 17 March 2015.

and placed against their will in institutions for people with psychosocial disabilities. The court found a number of violations, including that their living conditions amounted to inhuman and degrading treatment. Several participants in the research highlighted these judgments as helping to secure political support for the deinstitutionalisation process in Bulgaria.

Pressure to complete deinstitutionalisation in Ireland came from national sources, but ones external to the deinstitutionalisation process. Findings of very poor conditions in some institutions by the inspector of disability services in 2013 prompted urgent action. This often involved steps towards a transition to community-based services.[59] The findings also triggered an undercover investigation in one institution by the national broadcaster, provoking widespread public outcry and calls for action.[60] Media also played a crucial role in Bulgaria; stakeholders attributed the start of the deinstitutionalisation process for children to a documentary showing conditions in institutions (see Section 1.1).

Although participants felt that external pressure causes the deinstitutionalisation process to move more rapidly, they expressed concern that the reactive nature of these processes would not lead to quality outcomes. In Bulgaria, members of the independent living movement feared that the deinstitutionalisation process will aim to satisfy ESIF requirements rather than realise independent living in line with the CRPD. For them, the name of the national deinstitutionalisation strategy – the National Strategy on Long-Term Care – affirms institutional practices and principles by referring to 'care' rather than 'support'. This mirrors the terminology of the ESIF regulations themselves, which talk of the transition from institutional to community-based care.[61]

Driver 4: Persons with disabilities demanding deinstitutionalisation

"[T]here was a decision by somebody that he would engage with this and move out and he then packed his bag and there the bags sat, packed. Then it was everybody else scrambling around saying we have to do this […] and we had to do it quickly." (Ireland, local official)

Persons with disabilities living in institutions are often denied the opportunity to make choices and state their opinions and may, as a result, become unaccustomed to expressing their will and preferences (see Section 3.2.5). Despite this, they are an increasingly important driver of the transition from institutional to community-based support.

"Recently it has somehow become more common that persons with disabilities are familiar with the concept of self-determination and they demand their rights. […] They're not just settling for what's given to them and they are able to say what they want for themselves." (Finland, member of the local community)

Examples of persons with disabilities being strong self-advocates for deinstitutionalisation and, in turn, setting an example for others to emulate occurred throughout the research (see Section 3.2.2). In Ireland, one service user followed the lead of her friend who had transitioned to the community and campaigned for a home of her own (see story in Section 3.5.1). Similarly, one Italian man's insistence allowed him to achieve his dream of getting married and having a flat of their own (see box on *Jean's story*).

More generally, parents and staff highlighted the particular role of younger people with disabilities in demanding community-based services. Young people in Finland, Ireland and Italy do not tend to enter institutions, so are not themselves part of deinstitutionalisation processes (see Section 3.6.2). However, by demanding adequate community-based services to enable them to live independently of their parents, they support the development of such services. These can then be used by others leaving institutions.

This empowerment of young people with disabilities is closely linked to inclusive education, as the CRPD Committee has repeatedly underlined.[62] Many local-level participants in Finland and Italy, which has long-standing legislation on inclusive education, highlighted that children with disabilities are taught in school to be independent, and so automatically assume they will be.

---

[59] Ireland, Health Information and Quality Authority (HIQA) (2013), *National standards for residential services for children and adults with disabilities*, January 2013.

[60] RTÉ (2014), *Prime Time RTÉ Investigations Unit: Inside Bulgalow 3*.

[61] Regulation (EU) No 1303/2013 of the European Parliament and of the Council of 17 December 2013 laying down common provisions on the European Regional Development Fund, the European Social Fund, the Cohesion Fund, the European Agricultural Fund for Rural Development and the European Maritime and Fisheries Fund and laying down general provisions on the European Regional Development Fund, the European Social Fund, the Cohesion Fund and the European Maritime and Fisheries Fund and repealing Council Regulation (EC) No 1083/2006, OJ L 347, 20 December 2013, Annex XI, p.320.

[62] CRPD Committee (2017), *General comment No. 5 (2017) on living independently and being included in the community*, CRPD/C/GC/5, 27 October 2017, para. 88 and CRPD Committee (2016), *General Comment No. 4 on the right to inclusive education*, CRPD/C/GC/4, 25 November 2016, para. 46.

Promising practice

Building capacity for self-advocacy

In **Bulgaria**, the Plovdiv-based association Parallel World runs a project to help young people with intellectual disabilities to become more effective self-advocates. It focuses on enhancing their capacity and to take greater control over their own lives and to approach public authorities about the issues affecting them.

The association also works with these young people's families to expand their understanding of the principles of independent living and rights protection, and raises the awareness of both public authorities and the general public of the equal rights of people with intellectual disabilities.

For more information, see the association's website.

"Our perception is that we are not only witnessing a generational change but an epochal one. […] From childhood [younger persons with disabilities] start thinking about and fighting for what their life situation will be in their adult life." (Italy, manager of an institutional service)

Barrier 1: Insufficient, difficult to access or poorly assigned funding

Deinstitutionalisation is not an inexpensive process. It requires financial resources in the form of physical infrastructure, planning, training and staff recruitment. In the longer-term, however, participants indicated that it is less expensive to provide high-quality, community-based services than it is to run an institution, a view supported by other research.[63] They were often frustrated that others do not share this belief.

"Unfortunately, there exists very often, today, the perception that small facilities might be more costly, that closing the institution and bringing young people to live independently […] might be more costly." (Italy, employee of a community-based service)

Overall, participants felt that the funding allocated to deinstitutionalisation is insufficient**.** The financial crisis was cited by participants in Finland, Ireland and Italy a key factor in this. Looking at the issue in more depth, however, indicates a more complex picture.

One key concern is the unsustainability of project-based funding. Local officials in Bulgaria noted that although ESIF have funded a number of promising initiatives, they are time bound. National funding is often not in place to take over when they end, resulting in a gap during which persons with disabilities are left with little or no support. Even where state financing is available, it is often not sufficient to maintain previous standards and the quality drops: personnel resign due to lower remuneration or material conditions cannot be sustained. This is a common concern with ESIF projects, as highlighted in FRA's reports *From institutions to community living*.[64] Away from ESIF-funded projects, participants in Italy noted that the annularity of funding sometimes makes it difficult to plan longer term deinstitutionalisation projects.

Furthermore, long-standing criteria for funding allocation often mean that institutions receive significant funding, to the detriment of community-based services, as was noted by participants in Italy, for example. This prompted participants to call for more innovative funding solutions: participants in Ireland and Finland called for personal budgets that can be used to purchase support.

"Everyone says, money can help but we've done a lot of work without the extra money." (Ireland, manager of an institutional service)

However, participants, particularly at the local level, cited examples of significant achievements in the absence of specific or national funding for deinstitutionalisation. Committed service providers had found new and different ways to make of their own or other resources. One service provider in Ireland saw the large 'block grants' awarded to institutions as a driver of deinstitutionalisation. They allow the service to progress deinstitutionalisation as it saw fit, rather than following rigid national funding criteria. In Slovakia, the case study locality and Slatinka Social Services Home (see Section 3.1.2) forged ahead with deinstitutionalisation in the absence of the envisaged ESIF funding by using the budgets of the self-governing region and other philanthropic funds.

Several participants questioned whether complaints of insufficient funding mask a lack of willingness to implement deinstitutionalisation. In Finland, one representative of a local authority felt that lack of funding was used as an excuse for doing nothing towards deinstitutionalisation, and that a dearth of imagination in the use of existing resources is a more

---

[63] McConkey, R. et al (2013), *An evaluation of personalised supports to individuals with disabilities and mental health difficulties*, University of Ulster and Genio.

[64] FRA (2017), *From institutions to community living- Part I: commitments and structures*, Luxembourg, Publications Office; FRA (2017), *From institutions to community living-Part II: funding and budgeting*, Luxembourg, Publications Office.

I am Jean and I'm quadriplegic, meaning that I cannot move either my arms or my legs. I am from a family of seven and it was not easy to manage my impairment. So when I was five, I moved to a big institution in a large town – my father moved with my whole family to be closer to me.

At the beginning it was difficult: I felt disoriented and I missed my family. But later I found my feet. In the institution I was able to meet people living with the same condition and I became aware of the difficulties I was going to face.

I graduated as a business secretary. When I was 18, my father died and I needed to work. The disability benefit wasn't enough. We created a cooperative society to obtain jobs to carry out in the institution. In 1982, I found an external job. I wanted to work and I wanted a real job, with other people.

I found the right job for me: a big company where I was in charge of mail distribution. I really enjoyed this job, but unfortunately after three years the company closed. I felt I still needed autonomy. Together with the institution and support from staff of an NGO, we found suitable accommodation for me in a community located in the centre of Italy. It was a community not only for persons with disabilities. It was a completely different experience compared to the institution: there were no time schedules besides the meals and we had to organise our own days. I used to write for an internal magazine and we also used to deal with social problems...we were very active!

In this community I met my wife, Paola. She visited the community with her friends from an institution in Tuscany. I went to Tuscany to visit Paola. I met the director of the institution. When he saw that I was interested in Paola, he suggested that I could be integrated into a family shelter nearby, so we could be closer and avoid the journey. I moved in 1990. I spent two years at the family shelter. During this time Paola and I were preparing the documents for our wedding.

Getting a flat became an urgent necessity as Paola and I wanted to get married. But the bureaucracy was complicated. Our problems in getting married were not only bureaucratic but also practical. Paola's parents were opposed to the idea, they didn't want her to live with me; they would rather have her at home with them. But Paola was very determined and she won. We got married in 1995. We made it. We got what we wished for, what we wanted.

Now we live together. We have a care-giver who stays with us all day and sleeps at our place. She does the shopping and cooking. We get along with her. During the day a guy comes to help her with the housework. Both Paola and I work in the institution's cooperative societies: I am in charge of the wheelchairs and Paola of the estate office. During the summer, we go on holiday to the seaside with a group and we spend two weeks there. We spend important holidays with Paola's dad. "It was a journey in stages, but a very fruitful one".

JEAN'S STORY — ITALY

HUMAN STORY

significant barrier. In Ireland, some felt services are requesting unreasonably large sums to undertake deinstitutionalisation, because they do not want to implement it.

Barrier 2: Vested interests trying to block deinstitutionalisation

All Member States spend significant financial resources on services for persons with disabilities. FRA and other research consistently shows that this funding is disproportionately directed to institutional services.[65] This creates a complex set of interlinked financial and political interests. These interests, sometimes declared and sometimes unstated, are generally not linked to deinstitutionalisation specifically. Rather, they often relate to a desire to maintain the status quo. Section 3.5.5 addresses the related issue of staff concerns about poorer employment conditions in community-based services.

> *"And because the interests in the status quo are very powerful, they are very difficult to overcome. [...] The interests are related both to control and to money. Control usually goes with money and vice versa."* (Bulgaria, representative of a national disabled persons' organisation)

Many participants across a range of stakeholder groups expressed frustration with vested interests at the political level, within institutional service providers or both. The political power of large institutions was highlighted in Bulgaria, Italy, Ireland and Finland**.** Some institutions employ this power to further deinstitutionalisation (see Section 3.1.2). However, others use their considerable influence to lobby against or weaken deinstitutionalisation provisions. Participants cited concerns about the expense and complexity of transforming services, and a fear of losing power and prestige, as the reasons some institutional service providers oppose deinstitutionalisation. In Finland, for example, enabling young people with disabilities to move from their family homes into supported housing units has progressed more easily than the same move for older people living in institutions. Interviewees speculate institutions may have conflicting interests in the latter case, as they are effectively losing their clients.

> *"[Y]ou are working with the institution and you motivate clients, clients are ready, you have prepared the employees, and then all of a sudden, somewhere in the background something happens between the self-governing region and the director, and then just nothing. [...] So there was this grey politics, which is such a challenge."* (Slovakia, national policymaker)

In Slovakia, participants pointed to the role of corruption and anti-EU sentiment in blocking deinstitutionalisation in certain cases. In one region, participants mentioned a governor who refused to approve ESIF funding for deinstitutionalisation of two institutions. They attributed this to his Euroscepticism and negative attitude towards people with disabilities.[66]

Barrier 3: Deprivation of legal capacity

A large number of people with disabilities living in institutions in the EU are wholly or partially deprived of legal capacity.[67] This means that the decisions they make on financial, legal or personal matters are not legally recognised. Instead, court-appointed guardians make decisions on their behalf. The CRPD Committee's general comments on the right to independent living and equal recognition before the law (Articles 19 and 12 of the convention) underline the close interrelationship between the two articles, stating that "legal personality and legal agency are the bases for the realisation of independent living within the community for persons with disabilities".[68] FRA's 2013 report on legal capacity explores this issue in detail.[69]

The situation of legal capacity varies across the Member States covered in the research. In Bulgaria and Slovakia, participants reported that almost all people living in institutions are deprived of their legal capacity: the director of an institution generally acts as guardian for its residents. This makes it a significant practical barrier. In Finland and Ireland, new legislation looks to promote supported decision-making: attitudinal barriers predominate here. Bulgaria is also reforming its legal framework towards supported decision-making.

Across all countries, however, the deprivation of legal capacity has wide-ranging implications for how service providers view and treat people with disabilities, the research found. This is often tied to an underlying

---

[65] FRA (2017), *From institutions to community living- Part II: funding and budgeting*, Luxembourg, Publications Office; European Network on Independent Living (2018), *Briefing on the Use of EU Funds for Independent Living, Brussels*; Academic Network of European Disability Experts (2010), *The Implementation of Policies Supporting Independent Living for Disabled People in Europe: Synthesis Report*, University of Leeds.

[66] See, for example: SITA (2014), *Kotleba má výhradymávýhrady k projektom, BBSK môže prísťmôžeprísť o eurofondy*, *WebNoviny*, 10 October 2014.

[67] Mental Disability Advocacy Center (2013), *Legal capacity in Europe: a call to action to governments and to the EU.*

[68] CRPD Committee (2017), *General comment No. 5 (2017) on living independently and being included in the community*, CRPD/C/GC/5, 27 October 2017, para. 27; CRPD Committee (2014), *General Comment No. 1 – Article 12: Equal recognition before the law*, CRPD/C/GC/1, 19 May 2014.

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

paternalist approach to people with disabilities rooted in a belief that they either cannot or should not make decisions about their lives (see Section 3.2.4).

Participants said deprivation of legal capacity impedes deinstitutionalisation and independent living in important ways:

- It leads to or lengthens institutionalisation. One interviewee with a mild intellectual disability from Bulgaria explained, for example, how his mother decided to send him to an institution. To enable this, he was deprived of legal capacity and his mother became his guardian. After 10 years in an institution, his mother allowed him to move to a protected house. However, he remains deprived of legal capacity, and needs her approval for many of the things he wants to do.
- It contributes to risk aversion among staff, who are reluctant to let their clients go out alone as the institution would be liable if anything happened.
- It results in people being assessed as needing higher levels of support than they actually do.
- Guardians sometimes act in their own interest, usually regarding property belonging to people with disabilities.

While many national-level participants and DPOs welcomed the steps towards supported decision-making in Bulgaria, Finland and Ireland, service providers, families and frontline staff were generally less positive. Frontline staff in Finland, in particular, felt that new legislation implemented in 2016 to promote self-determination challenged their ways of working.[70] They questioned whether some persons with disabilities could achieve self-determination, sometimes likening their decision-making abilities to that of children.

"I've sometimes been thinking whether I would have given my own six-year-old child full rights to decide upon things. I don't know." (Finland, employee of a community-based service)

Participants tied steps to promote supported decision-making closely to family members' support for deinstitutionalisation. Some felt legal reforms provide a tool to overcome family reluctance.

"I think it's good that it gives us something to lean on when encountering challenging family members, who are very ready to define that, okay, she should wear this and she should use her money on this. We can say that, hey, we're starting with what Matti wants, and not what Matti's mother Maija wants." (Finland, employee of a community-based service, names are pseudonyms)

However, some service providers in Ireland feared that new supported decision-making structures could prove a barrier to the transition to community living, as that families opposed to deinstitutionalisation might influence their relative to oppose a move to community living.

Finally, some families feared that their relatives might be taken advantage of if they were allowed to make their own decisions.

"I tell you, if guardianship is abandoned for […] people with intellectual deficiency, people who don't know what they are doing, do you know what happens? One signs [a document] […] there are many sneaky people and youngsters: 'Come on, boy, sign this!' [The person] cannot even read but the bank will request money from him." (Bulgaria, family member of a person with disabilities)

In contrast, several participants reflected on how deinstitutionalisation promotes exercise of legal capacity. They noted that living independently in the community empowers persons with disabilities to make choices about their lives and gives them access to a range of people with whom to talk through decisions. In this way, it can be seen as a form of support to enable people with disabilities to exercise their legal capacity.

3.2. A change in attitudes towards persons with disabilities

"My view is that money is very important, and deinstitutionalisation is not possible without it, but attitude is even more important. The attitudes of all these different actors." (Finland, representative of the national Article 33(2) monitoring body)

Changes in attitudes and commitment to deinstitutionalisation are closely linked. Commitment to deinstitutionalisation is the product of a paradigm shift in the understanding of the role of persons with disabilities in society; likewise, commitments made will only be successful if attitudes change.

The attitudes of policymakers are largely revealed through the policy commitments they undertake and, crucially, the steps taken to implement them. This section focuses instead on the attitudes of the people who can make deinstitutionalisation a reality through their daily interactions with persons with disabilities: communities, staff and the families of persons with disabilities.

---

[70] Finland, Act on Special Care for Persons with Intellectual Disabilities *(Laki kehitysvammaisten erityishuollosta/ Lag angående specialomsorger om utvecklingsstörda)* (23.6.1977/519).

Key drivers		Key barriers
3.2.1 Changes in public attitudes towards persons with disabilities Deinstitutionalisation creates a 'virtuous cycle': as people with disabilities become more visible in the community, communities are more welcoming of them, making the transition process easier.	**A change in attitudes towards persons with disabilities**	**3.2.4 Institutional models of 'care' persisting** Strongly embedded beliefs that people with disabilities should be 'looked after' and 'cared for' both prevent people from leaving institutions and lead to the persistence of institutional practices in community-based services.
3.2.2 Media and individual stories redefining public perceptions of people with disabilities Positive representations of people with disabilities can help to reshape perceptions of disability and counter 'fear of the unknown'.		**3.2.5 Learned dependence of persons with disabilities** Institutionalisation often leaves people with disabilities without the basic independent living skills needed in the community.
3.2.3 Changes in staff attitudes towards people with disabilities Staff committed to independent living empower people with disabilities to transition to the community and set a positive example for other colleagues.		**3.2.6 Family resistance to deinstitutionalisation** Families are often reluctant to support deinstitutionalisation for their relatives because of concerns about the availability of community-based services and about safety and security in the community.

Driver 1: Changes in public attitudes towards persons with disabilities

"I remember when I was a child, [disability] was considered scary, we were even afraid that it might be contagious. Really. That was what it was like before, so we have made a lot of progress since then." (Finland, member of the local community)

Institutional settings serve to segregate persons with disabilities from the rest of the community. This, participants noted, leads to people with disabilities being viewed as 'different' and not part of society. Moreover, the invisibility of persons with disabilities creates and strengthens stigma and stereotypes.[71]

On balance, most participants, particularly at local level, felt that attitudes towards persons with disabilities have improved over recent decades. They viewed this as part of a 'virtuous cycle': deinstitutionalisation results in people with disabilities being more visible in the community, and increased visibility of people with disabilities in turn makes communities more welcoming of them.

---

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

Surveys assess attitudes towards persons with disabilities

While this qualitative research asked participants about their perceptions of attitudes towards persons with disabilities, several statistical surveys have sought to capture wider societal attitudes.

At the EU level, a 2015 Eurobarometer carried out across the 28 EU Member States and including 27,718 respondents, looked at perceptions of discrimination on different grounds, including disability. The 2015 survey, which builds on previous Eurobarometer surveys conducted every three years since 2006, revealed some positive developments in relation to openness of European societies towards their fellow citizens with disabilities. For instance, 63 % of Europeans have friends or acquaintances with disabilities and 87 % say they would be comfortable or indifferent if one of their work colleagues is a person with a disability. Moreover, a total of 67 % Europeans would be at ease with their sons or daughters having a relationship with a person with disabilities, but only 52 % think that people with disabilities are sufficiently represented in the media.

Several national-level surveys explore attitudes towards people with disabilities specifically in more depth. They show diverging results. Findings from a series of research projects on attitudes towards disability in the United Kingdom published in 2014 revealed that almost two thirds (67 %) of the British public feels uncomfortable talking to people with disabilities and nearly half (43 %) say they do not know anyone who has a disability. More worryingly, 38 % of those surveyed considered people with disabilities less productive than the general population and over three quarters (76 %) thought of people with disabilities as being in constant need of care. Finally, such negative attitudes are more prevalent in relation to people with intellectual and psychosocial impairments than those with other types of disability.

In Ireland, the National Disability Authority has conducted a nationwide survey on attitudes to disability every five years since 2001. The 2017 results showed an overall improvement in attitudes towards people with disabilities when compared to 2011 data, and have either returned to, or exceeded, 2006 levels. For instance, there was an increase in the level of agreement that people with all types of impairments can participate fully in life. Moreover, the 2017 survey revealed that 87 % respondents agreed or strongly agreed that people with disabilities should have the same access to housing as everyone else, as well as an increase in the respondents' levels of comfort with having people with different types of impairments as neighbours.

For more information, see: European Commission (2012), Special Eurobarometer 437 on Discrimination in the EU in 2015*, October 2015 p. 10, and 40-41; SCOPE (2014),* Current attitudes towards disabled people*, May 2014, p. 3, 7 and 8; and National Disability Authority (NDA) (2017)* National Survey of Public Attitudes to Disability in Ireland 2017*, p.13 and 36.*

Stakeholders gave concrete examples of this process. Communities in Bulgaria and Slovakia which strongly protested against deinstitutionalisation projects in their area gradually got to know the individuals with disabilities concerned and became far more supportive. In Ireland, two participants cited instances of members of the public raising concern about how staff members interacted with service users in public.

Even where deinstitutionalisation has yet to take place, the more the institution allows its residents to interact with the wider public, the more positive attitudes become. However, this is only a first step.

"[I]ntegration, inclusion [and] socialisation are crucial. [...] There is a very important thing that is letting the territory come inside the facilities, but it's important to take these facilities into the territory [...], that is, giving life to the social dimension of interaction." (Italy, employee of a community-based service)

Promising practice

Community inclusion of persons with disabilities

Participants in the research underscored the importance for successful deinstitutionalisation of regular opportunities for daily social interactions between persons with disabilities and members of the local community. They gave several examples of how to achieve this.

One concerns visits to a library in a large **Bulgarian** city. When persons with disabilities started visiting the library, they were accompanied by social workers. Now, many go there on their own to borrow books. Those who can then read the books aloud for their housemates who cannot. The library staff organise public readings and educational talks on various topics for service users from the sheltered housing. They also invite them to theatre performances and exhibitions, enabling them to take part in events with the wider community. These actions have a ripple effect, with service users increasingly invited to take part in workshops and events with other cultural organisations.

In **Ireland**, many staff and managers felt that shopping locally, even if no longer the norm for most people, was key to integrating people into the community.

"We have two guys in a tiny little village and [the staff] decided…we are going to split the shops, so this is John's shops and these are Mark's shops and [...], we are going to shop every day [...] because we are going to be generating opportunities to be bumping into people." (Ireland, manager of a service providing institutional and community-based services)

Driver 2: Media and individual stories redefining public perceptions of people with disabilities

Participants stressed the role of the media and individual stories of successful deinstitutionalisation in both reshaping perceptions of disability and countering 'fear of the unknown'.

The media can play a dual role. Firstly, positive images of persons with disabilities can provide a strong impetus in shifting perceptions (see promising practice). Secondly, media revelations of mistreatment of people with disabilities in institutions heighten public awareness and influence political agendas (see Section 3.1.3). However, participants noted that public concern with regard to poor institutional practices does not necessarily translate into how local community members themselves interact with persons with disabilities.

Promising practice

Positive media images of persons with disabilities

Local community members, in particular, highlighted the power of the media to change public attitudes towards persons with disabilities.

Positive media images are particularly widespread in **Finland**. An actress with an intellectual disability plays an important role in one of the most popular TV series in Finland, 'Salatut Elämät'. The punk rock band, Pertti Kurikan Nimipäivät, composed entirely of persons with intellectual disabilities was the Finnish representative in the Eurovision song contest. Participants across all categories felt that such images help to promote inclusion of historically marginalised groups, including persons with disabilities.

"[I]f I had the power, I would go to the film industry and the theatre industry and I would tell them: 'Dudes, your help is needed! We want a series – a disabled person, two Roma in another series, I want a Roma playing a leading role [...] I want people to see that there are normal people among them. And I want them to become examples to follow.'" (Bulgaria, member of the local community)

Participants also referenced individual success stories as key to convincing other stakeholders.

"An important driver would be the presence of local exemplars of the change in practice – much more impactful in my view than top-down legislation or master plan-driven approaches to engineering significant change." (Ireland, employee of an institutional service)

Here, too, the media has a role to play. Showcasing examples of people who have left institutions and live in the community help to counter negative perceptions of disability and build the confidence of people with disabilities to demand changes (see Section 3.1.4).

Driver 3: Changes in staff attitudes towards people with disabilities

While shifts in societal attitudes can shape and facilitate independent living in the longer term, implementation of deinstitutionalisation rests in large part with the staff working in disability services, whether in institutional or community-based services. Changes in their attitudes to the way they design and deliver services is therefore inextricably linked to achieving the promise of Article 19 of the CRPD.

"Staff are far more forward-looking than they used to be. They consider the future more, compared even to a family which is more scared or to public authorities that don't want to see it because it's not very politically beneficial. The staff have a different approach and many instruments they can apply and they dare to risk more." (Italy, representative of a family association)

The positive attitudes of staff who have embraced the concept of independent living is one of the main drivers of the deinstitutionalisation process, according to persons with disabilities and senior service managers. Such attitudes were evident in the approach of many of the staff members interviewed across the five countries. Changes in staff attitudes are closely tied to training and persistence of an 'institutional culture' in community-based services, as discussed in Section 3.2.4 and Section 3.4.2.

Many people with disabilities felt that the support of their staff, whether in institutions or community-based services, gave them the security to undergo the changes in their lives. These staff members also served as positive example and inspiration for their colleagues.

Managers of services reflected on how to bring more progressive attitudes into their organisations. Several felt that it was very difficult to change the attitudes of staff who had worked in institutions for many years, and preferred to hire new staff. In the case study locality in Ireland, these were often staff with little or no background in disability services.

"I'm not caught under looking for huge qualifications or anything. I'm looking for what's in your heart, what your skills are and what your life experience is." (Ireland, manager of a community-based service)

In contrast, participants in Slovakia reported that deinstitutionalisation is easier to initiate in institutions with a higher proportion of professional staff. However, they too noted that newly qualified social services professionals are more open to new and experimental working methods than long-term employees. Firstly, they learned contemporary working methods during their studies; and secondly, they are not used to existing and sometimes rigid working habits.

"Young employees are no longer burdened by the old system. They have a different way of thinking from the senior ones. They are more open to new challenges and they like to try new things whenever they have a chance. They are like friends with the clients. It commonly happens that a staff member takes a client to the cinema in the evening." (Slovakia, regional policymaker)

Barrier 1: Institutional models of 'care' persisting

"Things are definitely going in the right direction [...] but we need a model, we need to build real homes instead of new institutions." (Finland, local policymaker)

The persistence of institutional culture was identified strongly by all types of participants across the research as a major barrier to deinstitutionalisation. Institutional culture reflects seeing persons with disabilities as under the 'care' of staff. It contrasts with the CRPD model of persons with disabilities having choice and control over the support their staff provide. This barrier took two forms: either preventing people from moving into the community, or leading to the persistence of institutional practices in community-based services.

In some cases, participants felt that this was a problem throughout the system, from the top down. In Bulgaria, for instance, participants felt that the national bodies responsible for disability services work according to outdated principles of providing 'care', noting that this is what their employees and management are taught during their university or vocational training courses.

At a less senior level, participants in all five countries emphasised the difficulty of overcoming entrenched care-based models of service provision among frontline staff. Institution-like practices persisting in community-based services were noted in every country. These include: routines and curfews; strict schedules for meals and medication; and service users being obliged to undertake leisure activities as a large group, for lack of individual support services.

Many participants across stakeholder groups in Finland indicated that it is common for staff members in community-based services to treat persons with disabilities as a group and as objects of care**,** rather than as individuals with their own will and preferences.

"[S]ocial welfare for persons with intellectual disabilities in Finland has had an emphasis on nursing culture. Persons with intellectual disabilities have been nursed, treating them as objects. [Therefore] listening to the person's [wishes] and taking their views into account has not been developed." (Finland, representative of the national Article 33(2) monitoring body)

Participants also noted the tendency of well-meaning staff, and indeed families, to view service users with disabilities as children. Although this can signify the strong and caring relationships between staff and service users, the risk is that this results in over-protectiveness, where staff perform tasks for people with disabilities that they could do themselves.

"The colleagues do not work for 'big money', nevertheless, they give their best and they treat the clients as their own children." (Bulgaria, employee of a community-based service)

Participants linked this to the impact of long-term institutionalisation on all those involved. Some highlighted that persons with disabilities become so accustomed to the particular routines of institutional life that they continue them in community settings, despite having the opportunity to change. Others highlighted that staff also become institutionalised.

"The risk of institutionalisation is that the staff get institutionalised too. Institutionalisation entails many risks including losing sight of the dignity of the person in front of you who is not a person anymore and might become a subject with whom…you depersonalise the relationship" (Italy, local policymaker)

Many participants were clear that overcoming the care-based models presents a big challenge.

"Changing the people who have been working in the institutions for years, is a very hard, long-term process." (Slovakia, manager of a service providing institutional and community-based services)

Section 4.2 and Section 4.4 present some measures to address this, including training and recruitment.

Barrier 2: Learned dependence of persons with disabilities

"Many people, I have also been one of them, do not think that people need to earn their living. [In the institution], the food waits for me three times a day, [...] everything is prepared. They take 70 % of my disability pension and I use the remaining 30 % for my miserable life and the sense of taking responsibility is gone." (Bulgaria, person with a physical disability)

Participants in all five countries cited learned dependence as a barrier to deinstitutionalisation. Learned dependence is a widely recognised consequence of institutionalisation, as people do not learn – or forget – how to do tasks that are done for them in institutional settings.[72] This can range from basic skills such as preparing meals to the ability to reflect on and make major life decisions.

Participants gave concrete examples of how learned dependence impedes deinstitutionalisation. In many cases, it contributes to a reluctance among people with disabilities to leave the institutions they have lived in for many years.

"[I]t cannot be taken for granted that people living for many years in institutions are going to appreciate living a life of autonomy in a flat with friends, because spending many years in an institution becomes a dependence and it is a real barrier." (Italy, employee of a community-based service)

It also often leaves people with disabilities without the everyday independent living skills needed in the community. Staff in Slovakia reported that that a lot of work needs to be done to help service users who have recently transitioned to the community to overcome learned dependence and develop their full capabilities (see Section 3.5.2.). In Ireland, several services assign extra staff hours to those just leaving an institution, to help them acquire independent living skills.

"All services talk about creating independence and no matter what, all services struggle with it. Actually, what they create is dependence. [...] We don't allow them to make the cup of tea and then all of a sudden we realise we need to start trying to teach them how to make a cup of tea again." (Ireland, national official)

Barrier 3: Family resistance to deinstitutionalisation

"[O]ften the main resistance to the process comes from the family, I mean there are 50-year-old disabled people who still sleep in their parents' bed, so whose problem is this? The 50-year-old's or the 80-year-old's who can't let his/her son go?" (Italy, regional policymaker)

Families are sometimes extremely supportive of deinstitutionalisation, the research shows. Frequently, family members are among the most committed campaigners for independent living. However, the research also reveals that family resistance presents one of the greatest challenges to the transition to community-based support, including from the family home. Participants in Bulgaria, Ireland and Slovakia recounted cases where families had actively campaigned against the closure of institutions.

Participants identified two main causes of this resistance:

- the perception or experience of a lack of appropriate community-based alternatives to institutional services;
- fears for the safety and security of relatives living in the community.

Lack of adequate services in the community is a problem in all five Member States – and across the whole EU (see Section 3.5.1 and Section 3.5.2). In Bulgaria, families of people with disabilities said that they felt abandoned by the government and society. The lack of available support leaves family members – typically women – responsible for providing support, often forcing them to leave their jobs and/or sacrifice their personal lives. In recent years, support for children with disabilities has significantly increased. However, once the child turns 18, this ceases and the only option in many cases is for that young adult to enter an institution. This leads to long waiting lists for places in institutions. Many families of adults with disabilities in Bulgaria believe that deinstitutionalisation will mean their adult children returning to live in the family home. The burden created by the need to provide support, along with difficulties arising from often long periods of separation, means that this fear contributes to a strong reluctance among families to engage with the deinstitutionalisation process.

Even where some community-based services exist, however, families are often reluctant to explore these options.

---

[72] See: EEG (2012), *Common European Guidelines on the transition from institutional to community-based care*, Chapter 4; and 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, p.38.

"When a family runs into some sort of situation that requires an urgent solution, the provision [of social services] is so limited and the [institutional] system is so deeply rooted that they often see [institutional care] as the easiest solution. [P]eople have [developed] some kind of notion [of these services] and they cannot even imagine how it could work differently because they have never experienced it." (Slovakia, representative of a non-governmental organisation)

This is often tied to a belief that institutions are more secure, and that living in the community presents greater risks to the safety and security of their family members.

"Of course, the thing that always worries me is that when he goes out there alone, something might happen. You read about it every day. […] If somebody happens to notice that he's a bit different, he probably wouldn't know how to defend himself." (Finland, family member of a person with disabilities)

"Looking back, I remember the great fear: I have to say sometimes I went to check whether everything was alright: Did you iron the clothes? Did you switch off the iron? […] Make sure you don't answer the door to anybody." (Italy, family member of a person with disabilities)

This may reflect the widespread tendency to treat adults with disabilities as children. In cases where persons with disabilities entered institutions as children, some parents perceived them as having been frozen in time. As with staff, family members often referred to their adult relatives as children.

"[The discussions around deinstitutionalisation were] going on for a long, long time before I would agree to it, before I'd let go! He's still a baby, he was 40 two weeks ago!" (Ireland, family member of a person with disabilities)

"I was afraid she would run away [if she lived in the community] because when she was three she had escaped. But the psychologist said to me, you know, she doesn't do that now, she is 39 now so she doesn't run away now." (Ireland, family member of a person with disabilities)

3.3. Active cooperation between the people involved in the deinstitutionalisation process

Achieving deinstitutionalisation involves a complex web of different actors. This includes public authorities at the national, regional and local levels, as well as across sectors ranging from disability services to health, education and employment. But it also involves those without a professional role in deinstitutionalisation: the families, local communities and most importantly persons with disabilities who transition from institutions to life in the community.

This section looks at cooperation between these different actors, both horizontally – between different sectors, the community and families – and vertically – between different levels of governance. Where cooperation works well, it helps to drive deinstitutionalisation processes forward. Where it is absent, it creates both gaps and overlaps which act as significant impediments to progress.

FRA's reports *From institutions to community living* provide further information on cooperation between different actors involved in deinstitutionalisation across the 28 EU Member States.[73]

---

[73] FRA (2017), *From institutions to community living- Part I: commitments and structures*, Luxembourg, Publications Office; FRA (2017), *From institutions to community living-Part II: funding and budgeting*, Luxembourg, Publications Office.

Key drivers		Key barriers
3.3.1 Cooperation at local level Effective cooperation between different actors at the local level is an essential component of successful deinstitutionalisation. This can take the form of formal working groups or networks, or more informal working relationships between different actors.	**Active cooperation between the people involved in the deinstitutionalisation process**	**3.3.3 Lack of cooperation between and across sectors** Inadequate or ineffective cooperation can create confusion about responsibilities for implementing deinstitutionalisation. Participants reported a tendency to focus only on their role rather than on the process as a whole.
3.3.2 Cooperation with the families of persons with disabilities Involving families throughout the deinstitutionalisation process helps to overcome any resistance to the transition, and allows families to participate actively in the process.		**3.3.4 Lack of cooperation between different levels of governance** Gaps in cooperation between national, regional and local actors can leave practitioners feeling excluded from decision-making processes around deinstitutionalisation. It also increases the risk of developing policies that prove unworkable in practice.
3.3.3 Cooperation with actors bringing innovation and change Cooperating with third sector organisations and NGOs brings innovative ideas and experiences to the deinstitutionalisation process.		**3.3.5 Lack of cooperation with the local community** Not involving the local community in deinstitutionalisation processes can further entrench resistance to deinstitutionalisation.

Driver 1: Cooperation at local level

Much of the work to implement deinstitutionalisation is done at the local level. Reflecting this, participants identified cooperation between the various actors at the local level involved in planning and implementing deinstitutionalisation as particularly important. Indeed, they noted that cooperation at local level is often easier than cooperation between different levels of government. As stakeholders know each other and are in touch on a daily basis, cooperation can be faster and less formal.

Participants across the five countries, especially those in the case study localities, had experienced good cooperation at the local level. They provided a number of different models, covering both formal structures and informal working relationships.

In Italy, participants from across stakeholder groups at the national and local level identified so-called ‘territorial networks’ as one of the main drivers of the deinstitutionalisation process. Bringing together social cooperatives, private companies and other associations involved in providing services, participants credited these networks with facilitating a holistic approach to deinstitutionalisation. It also helps to root the process in the local community by involving a wide range of organisations active in the area. This in turn helps to overcome a number of barriers, including resistance in the local community to deinstitutionalisation and the risk that people with disabilities feel isolated after the transition. Participants in Slovakia and Finland described the usefulness of working groups set up to strengthen communication and cooperation between different actors (see promising practice box).

Promising practice

Inclusive working groups to plan deinstitutionalisation

Key to ensuring inclusion and participation in the community is bringing on board relevant local actors from the start of a deinstitutionalisation process. One way of doing this is to establish working groups to bring together these actors.

In **Slovakia**, the director of the Social Services Home in the case study locality convened a working group to draft a local community plan. It brings together relevant local actors including politicians; the social, healthcare and educational committees of the municipal office; social workers; teachers; and representatives of people with disabilities. The group was given a strong evidence base to work from, in the form of a survey which identified the main needs and challenges for users of social services in the area.

In **Finland**, a similar group set up by the municipality in the case study area plans housing for persons with intellectual disabilities, particularly still living in an institution. Members of the working group included persons with intellectual disabilities, their family members, service providers and actors responsible for housing and construction. The group was given a clear set of questions to discuss, with the overall objective of ensuring a good quality of life for persons with intellectual disabilities. The group met every month for a year.

Inclusivity and clarity of purpose emerged as the common success factors in these two examples. They brought together a wide range of stakeholders, including representatives of persons with disabilities, and were given a clear mandate and task to complete in an allotted timeframe.

An example of less formal cooperation came from Ireland. One provider of community-based services highlighted the importance of a good relationship with the local representative of the regulator of disability services. Even where the regulator highlighted problems, senior management were prepared to use this to motivate their staff and improve staff practices.

Participants in Bulgaria struck a note of caution, however. They felt that close relationships between different actors can lead to conformity and make divergence of opinions, which could lead to better results, less likely.

Driver 2: Cooperation with the families of persons with disabilities

Given the potential for families to resist deinstitutionalisation efforts, service providers participating in the research stated that it is very important to involve families of persons with disabilities at an early stage in the deinstitutionalisation process. This can help to build their support for the process and allay any fears, increasing the chance of success. For their part, families reflected on the difficulties created when they do not receive sufficient support, information and guidance during the deinstitutionalisation process (see Section 3.4.4.).

Service providers highlighted that having conversations with family members over time can build confidence, as can sharing the stories of other people who had successfully transitioned to the community.

> *"It's so much easier if you can have a conversation, 'I was wondering about, you know, would you consider it?' plant the seed, 'No, no, wouldn't consider it' then, a couple of weeks later you're kind of back and say, 'Well look would you talk to another family of somebody who has moved out, see what you think, even go see the house', you know so it's nearly like a sales person to actually get them to commit a little bit, you're on a road to selling it, in that sense, you know what I mean?"* (Ireland, manager of an institutional service)

By being provided information on how the process will unfold, family members can support it better and participate actively in its success. Such conversations can also help to avoid unrealistic expectations about deinstitutionalisation.

Some participants, particularly in Italy, highlighted that cooperation with younger parents is sometimes easier. They tend to be more aware of the human rights model of disability, making them more ready and willing to cooperate with local authorities and service providers to develop innovative solutions to foster the autonomy of their children.

However, some stakeholders noted the importance of not involving family members to the extent that persons with disabilities themselves are side-lined. In Finland, for example, service providers pointed out that it is essential not to assume that those moving want their parents involved. They might rather involve another close relative, or friend, or consider it no-one's business but their own.

Driver 3: Cooperation with actors bringing innovation and change

Participants also highlighted the usefulness of involving actors who may not always be viewed as natural cooperation partners, such as NGOs and the broader third sector. These stakeholders can bring innovative ideas and experiences to deinstitutionalisation processes. Participants recognised the important contributions of NGOs in:

- Advocating for legislative reforms to support deinstitutionalisation and independent living.
- Developing and piloting new community-based services: participants highlighted that the greater organisational flexibility of NGOs gives them the freedom to try new initiatives which can add significant value to the deinstitutionalisation process. These can in turn result in a wider range of service being available for persons with disabilities.
- Providing expert advice to institutions undergoing deinstitutionalisation, both as formal partners in deinstitutionalisation projects and through informal advice on an on-going basis. For example, the case study locality in Slovakia involved NGO experts in the development of its local deinstitutionalisation plan.

However, they also noted two challenges to NGO involvement. Firstly, such organisations do not exist in all areas where deinstitutionalisation is taking place. Secondly, NGOs in Bulgaria are not eligible to apply for pilot project funding under the relevant ERDF operational programme, restricting sources of financing for their activities in this area.[74] Some local authorities in Bulgaria expressed frustration at this restriction, which they felt deprived local administrations of alternative providers of community-based services.

---

[74] See: Operational Programme – Regions in Growth 2014-2020. Priority axis 1, investment priority 1.4 specifies that beneficiaries who can apply for funding are urban authorities (municipalities); priority axis 5, specific objective 1 specifies that beneficiaries who can apply for funding are municipalities and the Ministry of Health for the medico-social care homes.

Where NGOs do provide services, several policymakers and managers of institutions accused them of 'cherry picking' their users, leaving people with more challenging needs to local authorities.

Stakeholders in Italy and Finland pointed to the importance of cooperation between the public and the broader third sectors. The organisation of deinstitutionalisation in Italy means that funds for deinstitutionalisation are allocated to a range of organisations, including social cooperatives and family-run associations, based on calls for tender. Similarly, in Finland, municipalities often contract services to private service providers and the third sector. Participants highlighted that this contributed to ensuring a range of different services are available.

Promising practice

Developing skills and independence through a social agriculture project

A families' association decided to involve a group of school leavers with autism in a social agriculture project financed by the Tuscany region in **Italy**. Local farmers act as tutors and mentors to the young people, who learn about food production techniques and then produce their own jams, preserves and dried tomatoes. They also receive specific training on how to sell these products.

The project, initially for three years, was renewed for a further two. A small social enterprise was set up where three of the original participants continue to work. A private donation allowed them to purchase appropriate machinery. They cooperate with a well-known restaurant in a nearby town, which serves their products, and are now working to create other products together.

This type of cooperative enterprise, which involves both public financing and private sector resources, can play an important role in preventing institutionalisation of young people by developing their skills, independence and self-confidence.

Barrier 1: Lack of cooperation between and across sectors

The lack of cooperation between different sectors is a key barrier to deinstitutionalisation, in participants' view. It can result in overlaps, confusion or gaps in responsibilities for implementing deinstitutionalisation and providing different services for people with disabilities.

Many participants spoke of the need to recognise the complexity of the deinstitutionalisation process, and acknowledge that responsibility for its implementation extends beyond the social ministry to include, among others, national and local health, housing, education and employment authorities. Section 3.5. considers the practical consequences of the lack of shared responsibilities across sectors.

Reflecting this, participants in Finland, where the deinstitutionalisation process focused on provision of housing in the community, highlighted the importance of a holistic vision of deinstitutionalisation. They felt that a wider concept, incorporating issues such as education and employment in addition to living arrangements, is needed in the discourse around deinstitutionalisation. In practice, however, the fieldwork suggests that many local actors concentrate on their own roles, ranging from planning services to building new accommodation and providing supported employment, and do not feel strong ownership of the deinstitutionalisation process as a whole.

Participants linked the need for greater cooperation between the various services to ensuring that persons with disabilities can access them on an equal basis with others. Among the five Member States, Italy has a particularly strong cross-sectoral mechanism for ensuring equality of service, although the strength of cooperation in practice varies across the country. In the region where the FRA research was conducted, the healthcare and social services systems work together to meet the needs of persons with disabilities more efficiently. However, some coordination problems still emerge, particularly as service users become older.

"The fact that social assistance can be provided by just one service dealing with disability and using all these organisations to provide assistance is surely an advantage. [...] There is little fragmentation, except when you get to be 65 years old and you might need the RSA [Assisted Healthcare Facility – Residenza Sanitaria Assistenziale]. Maybe then you need the help of someone working in services for older people, with all the steps needed to access these services." (Italy, local policymaker)

Participants in Finland who actively sought out opportunities for collaboration recounted the obstacles they faced. One explained that she encountered difficulties as different services do not share a common understanding of the definition of disability. This created inconsistencies in service provision.

Lack of cooperation between and across sectors also reduces opportunities to share examples of good practice and learn from the mistakes of less successful initiatives.

Barrier 2: Lack of cooperation between different levels of governance

Effective cooperation between the different levels of government involved in deinstitutionalisation policy and implementation is also missing, participants across the countries covered by the research felt. Section 1.3 gives an overview of how responsibility for deinstitutionalisation is divided between national, regional and local authorities in the five Member States.

Participants expressed concerns about two main gaps in cooperation:

- Exclusion of local level actors from decision-making at the national level.
- Inconsistency and lack of clarity about the respective roles of different levels of government in deinstitutionalisation.

Practitioners and some local public authorities, particularly in Bulgaria and Slovakia, reported feeling excluded from decision-making around deinstitutionalisation. This took several forms. In Slovakia, participants noted a lack of communication from responsible bodies at the national level and the self-governing regions. Services participating in the first national deinstitutionalisation project said they had no contact with the relevant national government body once the project ended. This left them unclear about its future and plans for a follow up project. They also noted that there is no national body to address when encountering problems or challenges during the transition process.

The lack of cooperation has significant negative consequences. Practitioners and local authorities felt it left national policymakers without the practical knowledge of the challenges practitioners face, as well as detached from the everyday process of deinstitutionalisation. This increases the risk that they propose policies that prove unworkable in practice or which do not lead to the desired outcome. Managers and staff of social services felt left to apply these rules without fully understanding them and without the opportunity to request clarifications.

"We, at the lowest level, are the only ones who work for the people and with the people. The others, they work with [paper]. They know when something must be written down, but how it will work in practice – this is not so clear, what matters is that it is written down." (Bulgaria, employee of a community-based service for people with intellectual disabilities)

The second concern relates to the complex set of interwoven responsibilities for implementing deinstitutionalisation. Participants in Italy felt that the different responsibilities of the various levels of governance with respect to social policy and healthcare overlap. Lack of clarity about who is responsible for what can undermine integrated service provision.

Barrier 3: Lack of cooperation with the local community

"When we singled out the one [facility] that seemed to be the best [for deinstitutionalisation ...], the locals stood up against the idea. [...] [They] even appealed to their deputy in the regional parliament and we had to write back to them, but it was rejected. The parents opposed it. [...] [The project] failed eventually." (Slovakia, regional policymaker)

Some participants felt that failing to properly inform the public about deinstitutionalisation undermines the chances of success. This relates closely to community attitudes towards deinstitutionalisation (see Section 3.2.1.).

Overall, participants felt cooperation with local communities is lacking. In Slovakia, active resistance by the public to deinstitutionalisation in their local area was attributed to a lack of information. Community members in the case study locality, for example, were aware of the deinstitutionalisation process in their town, but viewed it as a 'novelty' and had no conception of it as part of a nationwide strategy. In Bulgaria, all groups of participants observed prevailing negative attitudes towards people with disabilities, especially those with psychosocial disabilities. However, none recognised the role they themselves could play in communicating with local communities or wider society.

Attempts to involve and inform local communities must be well thought through. Whereas in Slovakia, active resistance by the public to deinstitutionalisation in their local area was attributed to lack of public information, in Ireland, several service providers felt that similar protests were fuelled by 'town hall' meetings held by the service provider to inform the general public. Service providers learned from their initial mistakes and now take a much more informal approach to cooperating with community members in a more natural way – through encouraging them to call on their new neighbour for a cup of tea, for instance.

3.4. Availability of guidance to support the deinstitutionalisation process

When discussing how to achieve independent living, one issue that repeatedly emerges is the challenge of translating the principles of autonomy, choice and control into practice. Embedding these concepts in individualised community-based services that respond to persons with disabilities' needs requires a fundamental shift in often long-standing approaches into the design and delivery of support services.

> *"Active cooperation has to be translated into guidelines that can be applied in practice to ensure its accountability and its continuity."* (Italy, representative of a disabled persons' organisation)

Guidance on how to implement deinstitutionalisation is one tool to help all those involved achieve this transformation. Participants from across the countries and stakeholder groups covered by the research emphasised the importance of guidance, in particular for the practitioners responsible for implementing deinstitutionalisation in their daily work. This section presents examples of guidance participants had received and used to support their work, and highlights areas where they felt more guidance is needed.

Despite underlining the importance of practical guidance, many participants sounded a note of caution. A manager of a service currently being deinstitutionalised in Ireland warned against "going down the road of a system to put in place" and underlined that the essence of the person-centred approach required by the CRPD is that no single approach suits everyone. Guidance in the form of standard operating procedures risks impeding deinstitutionalisation and independent living.

Key drivers		Key barriers
3.4.1 Pilot projects showcasing how deinstitutionalisation works in practice Visiting pilot projects and learning exchanges allows stakeholders to acquire new knowledge and ideas on how to implement deinstitutionalisation. **3.4.2 Staff (re-)training and recruitment** Recruiting new staff and re-training existing ones is an essential component of instilling an independent living philosophy in disability services.	**Availability of guidance to support the deinstitutionalisation process**	**3.4.3 Insufficient guidance from national to local level** Lack of actionable guidance from national policy makers makes it more difficult for practitioners to implement deinstitutionalisation law and policy in practice. **3.4.4 Insufficient preparation and information for persons with disabilities and their families** Lack of information about how and when deinstitutionalisation will take place can create confusion and reduce the ability of persons with disabilities and their families to participate actively in the process.

Driver 1: Pilot projects showcasing how deinstitutionalisation works in practice

A variety of participants across the five countries – from the national and local levels, and including officials, staff and persons with disabilities – cited the importance of opportunities to observe pilot projects on deinstitutionalisation. Seeing how these projects operate in practice, and having the chance to speak to the people involved in establishing and running them, gave participants concrete examples of steps to emulate in their own work. They identified learning about these projects, which often go beyond national policy, as more important than the more theoretical guidance they sought from policymakers (see Section 3.4.1.).

In many cases, participants mentioned the importance of stepping outside their national context to visit pilot projects and participate in learning exchanges elsewhere in other countries (see box). They also highlighted how exchanges and cooperation with NGOs and DPOs, including visits to innovative services run by these organisations, provides inspiration, expert advice and know-how to move the deinstitutionalisation process forward (see Section 3.3.3).

Promising practice

Learning exchanges

A variety of stakeholders had participated in learning exchanges. They recounted how these visits provided them with greater understanding of how deinstitutionalisation might work in practice and exposed them to innovative ways of working.

In the case study locality in Slovakia, frontline staff visited community-based services in the Czech Republic, alongside managers and regional officials. They deemed this a significant tipping point in changing ingrained models of care for the staff members concerned.

In Finland, the board of directors and management of a federation of municipalities travelled to Scotland to observe community-based services there. After the visit, these leaders became much stronger champions of independent living and advocates of personal budgeting, participants explained.

Participants also highlighted the value of learning visits for persons with disabilities. In the Irish case study locality, a self-advocacy group of persons with intellectual disabilities visited persons with intellectual disabilities in Bulgaria. The Irish group helped to raise money for their Bulgarian colleagues to establish their own independent living community and self-advocacy organisation.

"When we met with people, for instance from the Czech Republic, who already had their experience and who used concrete examples to [show the employees] why the existing system was not good, that was basically the moment when tables began to turn, bit by bit. That's when the [institution's] director along with her team gradually began to change their perception of the nature of services they provided." (Slovakia, regional policymaker)

Driver 2: Staff (re-)training and recruitment

"Those [of us] who work [with people with disabilities], we have to change, and after that the change will spread. If we don't change, it will be difficult to expect that other people will change." (Italy, employee of a community-based service)

Instilling independent living principles in services for persons with disabilities rests in large part with the staff who run and work within them. Participants emphasised the crucial role of changing the mind-set of staff in driving successful deinstitutionalisation and avoiding the persistence of institutional approaches in community-based services (see Section 3.2.3. and Section 3.2.4.). They identified two main ways to do this:

- Recruiting new staff.
- (Re-) training existing staff to implement independent living principles in their work.

Many participants felt that the best way to avoid bringing institutional habits into community-based services is to recruit new staff to work in these services. Without having any experience of working in institutional services, these staff are likely to find it easier to reflect independent living principles in their work, participants felt.

In the Irish case study locality, managers adopted a modified version of this approach. They provide the opportunity for staff who had worked in the institution, but not as 'care' staff to retrain as support staff in the community. Several staff members, including previous canteen or maintenance staff, took up the chance. These staff are familiar with service users, but not necessarily influenced by models of institutional care. Moreover, it provides employment for people who might otherwise lose their job as the institution closes.

Re-training existing support staff is, however, a more common model. The importance of re-training staff cannot be understated, particularly of staff working in institutions who are committed to deinstitutionalisation. Training enables these staff to develop different skill sets and a greater awareness of the human rights-based model of disability, participants explained.

Participants highlighted the specific value of re-training existing staff. Many people working in institutional settings for long periods build up strong relationships with the service users, and can provide a sense of continuity and stability. Although changing the attitudes of these staff is a difficult process, participants felt it is possible through good training.

"It was about the staff too, because [...] the staff that in that moment was working to send these persons out, they were institutionalised too. [...] So if the staff doesn't undergo a reset we risk creating flats, for example, which are a more institutionalised than the institution itself" (Italy, employee of an institutional service)

The positive impact of successful training is clear. Several participants indicated that it played a crucial role in reaching the point at which stakeholders understood the change that deinstitutionalisation requires.

"I believe [the change occurred] when the training process was launched and we actually began to discuss what is the essence of the entire process. [The] education process was the moment when the information began to flow in and [the employees] began to discuss that [deinstitutionalisation] really made sense for the clients and about the quality [of services provided]. And this information simply began to change." (Slovakia, regional policymaker)

Barrier 1: Insufficient guidance from national to local level

One of the frustrations expressed especially by local level participants concerns a lack of guidance from the national to local level. This particularly relates to how to translate the principles of deinstitutionalisation enshrined in national legislation to practical realities at local level. This concern links closely to the view that local stakeholders are excluded from national decision-making processes so policy does not reflect the situation on the ground (see Section 3.3.5.).

"The problem was that [the Implementation Agency's] idea at the beginning absolutely did not correspond to reality. As if the philosophy they adopted…completely ignored the argument – 'Wait a moment, these people have never heard of deinstitutionalisation'. […] Changing people's way of thinking is the hardest thing." (Slovakia, regional policymaker)

These local participants felt that more effort is needed to explain how to implement a person-centred approach in practice. When they asked for clarification, however, the guidance they received merely repeated key policy lines, giving little additional value. This creates significant frustration.

"With the current regulatory framework all my colleagues are scandalised, they don't know what to do. […] You ask a question and they answer 'Article so-and-so'. But I ask concretely [how should I proceed with this case?], and again I receive 'Article so-and-so', directly rewritten from the framework which I can read by myself." (Bulgaria, director of an institutional service)

Although they were not evaluated by the participants in the research, an example of guidance comes from Italy, where the Ministry of Employment and Social Policies issued guidelines for the development of independent living projects in 2017.[75] These guidelines build on the second national plan for the promotion of the rights and integration of persons with disabilities. Furthermore, the National Observatory on the Conditions of People with Disabilities – the national monitoring body under Article 33(2) of the CRPD – promotes exchange of good practices at the national level.

For their part, participants at the national level were frustrated by the difficulties of overcoming institutional models of care, despite what they felt to be clear legal and policy direction.

Barrier 2: Insufficient preparation and information for persons with disabilities and their families

"What's happening now is that these people are setting us up to fail […]. After 40 years in an institution, they can't just all of a sudden overnight throw you out say off you go in the morning on your own." (Ireland, person with a physical disability)

Lack of preparation, guidance and information for those leaving institutions was identified as a significant barrier by participants at the local level and by persons with disabilities themselves. It can leave people with disabilities and their families unclear about what will happen to them and when, reducing their ability to be active participants in the process. Moreover, not having time to prepare for the changes associated with moving to the community, including developing independent living skills, can reduce the likelihood of it being successful (see Section 3.2.5.). It also contributes to family resistance to deinstitutionalisation (see Section 3.2.6.).

Information and guidance for those leaving institutions varies widely across and within the five countries covered by the research. In Finland, for example, the case study locality provides relocation training to persons with intellectual disabilities, their families and staff (see Section 3.5.1.). This covers general and practical issues concerning the move, including information about what will happen during the deinstitutionalisation process. Both the staff and managers of disability services perceived this training as a key element of success. In Bulgaria, in contrast, staff and management of both institutions and community-based services highlighted that there was no preparation or process to guide people with disabilities and their families through deinstitutionalisation.

In many cases, short transition times left little time to provide information or prepare people with disabilities and their families for the process. For instance, stakeholders in Slovakia felt that delays in implementation of the first national deinstitutionalisation project meant that the individuals moving to community living were ill-prepared. They wondered whether a slower process taken in several steps would be preferable, a view not shared by national authorities. Similarly, participants

---

[75] Italy, Ministry of Employment and Social Policy (*Ministero del Lavoro e delle Politiche Sociali*) (2017), Guidelines for the presentation of projects in the area of independent living and inclusion in the community of persons with disabilities (Linee guida per la presentazione di progetti in materia di vita indipendente ed inclusione nella società delle persone con disabilità).

in Finland gave two examples of a rushed process, which they blamed for a lack of adequate information and ensuing confusion. In one instance, the housing provided for a person with intellectual disabilities was in a different place than his parents had expected. In another, a person was relocated to a housing unit where the level of support was too high.

Other participants, however, argued in favour of shorter preparation periods and spoke about 'over planning' as potentially hindering the process given the inevitability of unexpected issues arising.

> *"The over planning of the process and having to have all the plans in place before anything can happen, people need a plan but not one that covers all eventualities therefore it never happens."* (Ireland, representative of a disabled persons' organisation)

Managers at the local level often felt that a lengthy information process and the final decision about community living options should not be completed in institutional settings. Firstly, this can delay deinstitutionalisation, and secondly it is often only after moving out of the institution that a person's true potential becomes clear. In the case study locality in Ireland, for instance, very short transition periods were generally favoured, partly because they reduced the scope for lengthy deliberations with family members and support staff. This did, however, sometimes mean that individuals moved several times before finding a suitable living arrangement.

3.5. Practical organisation of the deinstitutionalisation process

The ultimate goal of deinstitutionalisation is to enable people with disabilities to live ordinary lives in ordinary places; to live independently in the community on an equal basis with others. 'Community living' should be indistinguishable from the way anyone else lives their life. The organisation of deinstitutionalisation in practice is a key determinant of whether this goal will be met.

Participants were clear that having a range of high-quality support services for persons with disabilities in the community, and ensuring that services available to the general public are available and accessible to persons with disabilities, is central to successful deinstitutionalisation. This section looks at what participants experienced as the drivers and barriers of developing appropriate and responsive services in the community. Many of these relate to housing options, indicating the key role that accommodation plays in deinstitutionalisation and in the services that people with disabilities receive.

Notably, participants identified many more barriers than drivers related to this issue, reflecting the profound lack of suitable community-based services.

Key drivers		Key barriers
3.5.1 Individual support plans for persons with disabilities Individual plans can help to identify an individual's wishes and support persons with disabilities during and after deinstitutionalisation. **3.5.2 Developing independent living skills** Opportunities to develop everyday skills, for example in so-called 'training apartments', help to equip people with disabilities for life in the community.	**Practical organisation of the deinstitutionalisation process**	**3.5.3 Lack of specialised support services in the community for people with disabilities** The absence of appropriate community-based services for persons with disabilities prevents people from leaving institutions and impedes the full realisation of independent living in the community. **3.5.4 Inaccessible general services, including housing, health and transport services** Many services available to the general public are inaccessible for persons with disabilities, leaving them without crucial support and unable to participate in community life on an equal basis with others. **3.5.5 Inflexible rules and regulations on the provision of services to people with disabilities** Excessively rigid rules and regulations can perpetuate an institutional culture in community-based services and suppress innovation. **3.5.6 Lack of employment opportunities** People with disabilities face numerous barriers to entering the labour market, depriving them of a crucial route to financial stability and social inclusion. **3.5.7 Staff working conditions** Concern among staff that their working conditions will deteriorate as a result of deinstitutionalisation can undermine their support for the process.

Cathy explains that she comes from a large family, and lived at home until she was 18 and went to a normal school, although, “Well, I didn’t go all that often!” she says, laughing. When she was 18, she was sent to an institution for women with intellectual disabilities. “I don’t know why; my mam just told me it would be better for me.”

“I was up in the main house at first, it was big dorm rooms up there. Eventually I moved down to [another unit] and I got my own room. The staff were still on duty at night though, they used to open the door at night, checking you were OK. There would have been a lot of people in that house.

“When they first started talking about moving out into the community, I wasn’t too sure about it. I didn’t know what I was going to face. But I said, sure, I’ll give it a go.

“I moved into a house with four other girls. That didn’t suit me at all, though, they expected me to do everything. I said, I have to get out of here. I saw my friend [Bernadette], she was in [Unit C] with me. She got to move out on her own, in a house on her own. I said, that’s what I want. I used to go up to [the institution] every day after work, I was telling [the manager in charge], ‘I have to move out, I want to move out’.

“My family didn’t let it happen for a long time, though, they were dead set against it. They didn’t think I’d be able to do it, living on my own. In the end, [a support worker] came down with me to [the family home] and I told my sister: ‘That’s it, I’m moving out, I need my own space.’ And so they said: ‘Well, alright then Cathy.’

“I went and viewed apartments myself, with [the support worker] and my younger sister. I saw this apartment and I said: yes, this is the one. I have my own balcony, with a few plants, and I can see over to the river from the balcony. I have a spare room, and my sisters come and stay. My name is on the lease, and if I have any problems, the landlord comes, no hassle.

“I go to work from 10.00-14.00, three days a week, but I get the bus so I’m out from 8.30 to 4.00. I go to the local day service on Wednesday mornings, and I’m into all the community activities here, the youth club, the ladies’ group. The neighbours are friendly, they called over when I first arrived, to see if I was ok.

“I don’t mind being here on my own in the evenings, I’m tired, I’ll watch a bit of telly. I don’t stay here on my own on the weekends, though, it might be a bit lonely. So every second weekend, I go to [Louise, her care worker]’s house, she lives with her partner on a farm. Every other weekend, I go and stay with my friend [Bernadette, another service user] in [principal town]. There’s no staff there, just the two of us for the weekend.

“What else do I need in my life? Nothing, I’m happy the way I am.”

CATHY’S STORY
IRELAND

HUMAN STORY

Driver 1: Individual support plans for persons with disabilities

Some participants, particularly at the local level and including persons with disabilities themselves, highlighted the positive role of individual support plans. While these are not always specifically linked to deinstitutionalisation, staff felt they can help to achieve greater independence in community living. Some participants saw such plans as a useful way of discovering the individual's wishes. Two examples illustrate how these plans can help to ensure services are tailored to the individual.

In Ireland, person-centred plans have been used in disability services since the mid-2000s and are now a statutory requirement.[76] Although most participants viewed them positively, some felt that person-centred plans are sometimes unrealistic or overly rigid.

"How do we get a good life for people, rather than getting a good person-centred plan? That would probably be it in a nutshell really, isn't it? And we struggle with it all the time, really." (Ireland, employee of a service providing institutional and community-based services)

Italy has adopted a similar approach. Social assistants help their clients to design an individually tailored approach to accessing services.

A second approach, more specifically tied to deinstitutionalisation, comes from Finland. As part of relocation training, relocation coaches work with persons with intellectual disabilities, their families and staff members to plan their transition. All participants felt this contributes to a smoother transition process.

"In the past, when I was working in an institution [...] the resident just moved [to the community]. Of course you gave good information, as much as you could possibly give, but the change was quite sudden for the resident. So now it's really wonderful that we have a relocation coach working for the best for the client, and we're trying to find a good solution for the client." (Finland, employee of a community-based service)

Driver 2: Developing independent living skills

Providing opportunities to improve independent living skills not developed, or lost, during periods of institutionalisation helps to equip people with disabilities for life in the community (see Section 3.2.5.). Participants felt that this contributes to successful deinstitutionalisation by making the greater independence associated with life in the community a more realistic prospect.

"Without making their own decisions about their own lives, people will never find a way out of situations that life brings. That applies to 'healthy' people as well as to people with disabilities. In my opinion it is linked to one rule; that life, regardless of disability, always brings something new and incites the occurrence of new situations and circumstances." (Slovakia, person with a disability)

One practical example in place in Italy and Slovakia is the use of 'training apartments' for people with disabilities. These are apartments operated by disability services that aim to bridge the gap between institutional and community-based services. They look to mirror community-based settings and allow people with disabilities preparing for transition to learn everyday skills such as shopping and cleaning, and get used to a new environment.

"[S]ince they had autism they needed to get used to the novelty of the flat, to go shopping, to prepare their own meals together with the staff. So, at first staff undertook preliminary work, along the lines of, 'Ok, let's decide what to eat and let's go shopping and we'll have lunch in this flat only on one day, then two days, then three, then we'll go there to sleep' [...] They got used to it, giving them this possibility of a new reality, so these guys now hoover and do the cleaning." (Italy, employee of a community-based service)

Participants felt that this gradual approach can help make the prospect of deinstitutionalisation less daunting for people with disabilities and their families by introducing some of the most significant changes step by step.

However, several participants highlighted the risk that excessive focus on developing independent living skills could set unrealistic expectations. They cautioned that persons with disabilities should be given the opportunity to make mistakes as they transition into the community, without this being viewed as an 'inability' to live independently.

"[People with disabilities should] be given the opportunity to fail. So not giving up if they don't succeed right away, but giving them the chance, just like us, when we have become independent and moved away from home when we were young, at least I didn't do everything right during the first year." (Finland, employee training persons with disabilities undergoing deinstitutionalisation)

---

[76] Ireland, National Disability Authority (2005), *Guidelines on person-centred planning for the provision of services for people with disabilities in Ireland*.

MARTINA'S STORY — SLOVAKIA

HUMAN STORY

Martina is 21 years old and was raised in a children's home in the eastern part of Slovakia. From there, she was moved to a Social Services Home, probably when she turned 18. Now, she lives in a supported living flat, provided by the management of the Social Services Home, with six other people.

She tells us what deinstitutionalisation means for her. "Before I moved to the flat, I lived in the institution. The main difference is that in the institution I had to share a room with seven other clients – all of them were girls. The boys had a different room in the same section of the building. Now I share a room only with one girl – she is my best friend.

"Last year, I was told by the director of the institution that I had been selected as one of six individuals for deinstitutionalisation. The director had a meeting with all of us clients and explained the process of training and moving to the flat. They provided us with information about what it would look like and what we can expect from the process. I was asked whether I would be willing to move to the flat and I agreed; I was looking forward to moving to the flat.

"As the first step, we moved to a 'training flat'. The director described the whole process to us – that we would go to the training flat to learn all the skills necessary for independent living and, after that, we would move to a supported living flat, outside of the institution.

"The training flat was equipped in a more modern fashion and it was cleaner and nicer than the institution. I could bring pictures and photos and put them on the walls. Since only two of us share a room, I had more space for everything.

"We learned how to prepare food, wash our laundry, iron our clothes, how to count money, how to go to a shop and buy things, how to buy tickets for the train or bus. Sometimes we went for walks with our instructor to learn how to get oriented in the town.

"A year ago, we moved to the supported living flat. We call it 'home'. At the beginning, I was afraid to go there, because I could not imagine what it would look like and I did not know anybody in the neighbourhood. The flat is located high in the block of flats and at the beginning I was scared of the height. I did not even go on to the balcony. Now I do.

"Now I have some friends in the block of flats – three girls from the lower floor. Sometimes we chat when we are waiting for the lift or when the girls play in front of the block of flats. I do not have keys and never spend time in the flat alone. We always have some sort of supervision or 'company' from the instructor or another employee of the institution.

"I would like to visit my family one day, but I don't believe it will happen. My family visited me only once. I would also like to live even more independently than now – having my own family. But I don't know whether it is possible, it's just my dream. My dream is to have a proper job outside the institution. I would like to work as a nurse for older people. I want to earn money since I only have my disability pension, which is very low."

Barrier 1: Lack of specialised support services in the community for people with disabilities

Article 19(b) of the CRPD requires that persons with disabilities "have access to a range of in-home, residential and other community support services, including personal assistance". There is a huge number of possible specialised community-based services for persons with disabilities. These can range from personal assistance – the only service specifically mentioned in the CRPD – to day-care centres, in-home support and peer support.[77]

Participants from all the countries covered by this research, however, reported that such services are lacking in practice. They identified this as a key barrier to deinstitutionalisation in two key ways. Firstly, the lack of such services prevents people from leaving institutions, as they remain in many cases the only source of specialised support. Secondly, it impedes the full realisation of independent living in the community, as the absence or unavailability of appropriate support curtails people with disabilities' choice and control over their lives. Section 3.5.4. looks at issues associated with accessing general services available to the public.

"They come to us and say 'He should be placed... somewhere!' He should – but we, as social workers, do not want to place him in social service, or specialised and residential service; we would like to leave him in the family environment, right? We would like to offer him some form of daily, weekly support, but if there isn't any in the municipality? We have nothing to offer! No personal assistant, no social assistant, no home help – nothing!"
(Bulgaria, local official)

In Bulgaria and Slovakia, participants indicated that very few support services for persons with disabilities are available in the community. As a result, people with disabilities face a choice between institutional settings or living with their families without specialised support. In the few cases where people have moved to supported living accommodation in the community, this leaves them reliant on services provided by institutions.

"[Deinstitutionalisation cannot work] without having community services in the town. [...] [Persons with disabilities] will be living supposedly independently, in [supported living] houses; that is fine. They won´t be in a large institution, and that's fine as well. But we continue providing all services to them, because we have no other possibility. They have nowhere to go for those community services." (Slovakia, manager of an institutional service)

Where some community-based services are in place, three closely interrelated issues emerged concerning their appropriateness. Each runs counter to the vision of independent living set out by the CRPD Committee:

- Services are tied to particular living arrangements.
- Provision of services is based on a 'one size fits all' approach, and are not tailored to the needs and wishes of individuals.
- Regional variations in availability of services.

Throughout the research, the situations participants describe indicate that support for most people leaving institutions is expressly linked to particular living arrangements. This means that the support they can access depends on whether they live, for example, in a group home or in their own apartment or house, rather than on their preferences for one type of support over another.

Participants explained that, in their view, this means that even after physical relocation is completed, deinstitutionalisation is not realised. One service provider in Finland reflected that "walls are not a problem"; instead the more important challenge is to develop services that meet the needs of the residents with intellectual disabilities.

This is closely tied to services being designed for groups of persons with disabilities, rather than on the basis of individual preferences and needs. In Bulgaria, participants linked this to the system of state funding, in which deciding what social services are available is done centrally.

One particular gap is in the availability of personal assistance. In many cases, participants across the five countries reported, people with disabilities are expected not only to live together but to share support staff and to undertake activities as a group. This prevents them from participating in community life on an equal basis with others.

"It makes me sad that they have to go as a group. The [staff] don't always have the resources to attend to them as individuals. For instance, if one of them comes and asks 'Can you come swimming with me?', then the [staff member] says 'Sorry I don't have time. I'm alone on the night shift.' So they always have to do everything as a group." (Finland, member of the local community)

Participants also highlighted regional discrepancies in the availability of specialised community-based services. Service providers and parents stated that the quality and quantity of available services often depend on where individuals live. For example, Finnish stakeholders noted that the content and length of relocation training – which they valued highly – depend on the extent to which the

---

[77] FRA (2017), *Summary overview of types and characteristics of institutional and community-based services for persons with disabilities available across the EU*, Luxembourg, Publications Office; EEG (2012), *Common European Guidelines on the transition from institutional to community-based care*.

TANYA AND STELLA'S STORIES — BULGARIA

HUMAN STORY

Tanya is 24 years old. She lived in an institution for children with intellectual disabilities from the age of three until she was 'selected' and moved to an institution for children with physical disabilities. There she met her best friend, Stella, who had lived in the same institution since she was three. In time, they became best friends and shared a room.

When the deinstitutionalisation process for children began in Bulgaria in 2014, Tanya and Stella had to answer questions in front of a commission of 10 people, most of them strangers. The commission asked each of them where they wanted to go. Tanya chose to go to her home town, and Stella to go with her, as she had no personal preference but the two didn't want to be separated. At first, the coordinator of the commission was adamant that Stella and Tanya should be separated, but after discussions with Tanya and an NGO activist, she agreed to let them stay together.

By choosing to go to the new town, Tanya and Stella had no idea where they would be living. They moved to a protected house where, after a short time, new housemates moved in. Stella was disappointed because she expected to live with people who could communicate but none of them could speak. At first, Stella was only given blended food because her supporting documents said she cannot eat solid food, and it took Tanya's intervention with staff members to correct the mistake.

The two young women, being among the people with milder disabilities in the house, assisted the staff in taking care of other clients, writing documentation and sometimes answering the phone. They had full access to their documentation and discovered another mistake in Stella's documentation – she is deprived of legal capacity.

Tanya and Stella's lives changed when a person with psychosocial disabilities came to live in their protected house. He was aggressive: he threw food at them, he tried to push Stella down the stairs several times and locked her in her room. They were constantly harassed and had no privacy, even in their room. These problems made them plan to leave the house and rent a flat. The staff and Tanya's parents tried to convince them not to. The staff said that they have everything they need in the protected house, but did not promise to put an end to their problems with the aggressive resident. Tanya's parents react negatively to her plan, fearing that she might come to stay with them.

They moved into a flat and lived alone for almost two months. They had arguments with their landlord as they had to provide access to a common yard via their flat. Stella was the first to want to go back to a residential social service. Tanya did not want to return and they had an argument. A month after moving in, they filed an application to go back to the protected house. However, although their places had not been taken, the director refused to take them back. They were told that they could be accommodated in a family-type centre, a residential service with a more restricted regime than the protected house. They were given a date to move and a list of required documents to bring. The list included a number of medical assessments which the two girls had to organise alone, without any assistance, information or transportation. Stella pushed Tanya's wheelchair through the town several times on hot summer days, so they could obtain all the documents they needed.

In the end, they succeed in obtaining all the documentation in time and move into the residential service where they again share a room. They are still living there. Both hope they can find jobs. Stella has a long-distance relationship and she may eventually move to live with her boyfriend. Once they have lived in the town for five years, they will be eligible to apply for municipal housing. Tanya does not rule out this option but Stella is reserved about it, scared of what happened when they were alone in their flat. Tanya and Stella are aware that at some point in their lives they will go their separate ways, but they will still keep thinking of each other as sisters.

relevant municipality is willing to purchase this service. Some professionals thought that the case study locality does not purchase enough relocation training, while providing too much support within the institution.

This often relates to a wider rural/urban divide in service provision, which sees a greater variety of services available in larger cities than in smaller towns and villages. Stakeholders in the case study locality in Slovakia, for example, reflected on how it is typical of smaller localities with an almost complete lack of community-based services. Participants stressed the need to involve a wide range of actors, from local NGOs to civil initiatives and religious organisations, in creating these services.

Promising practice

Schemes to enhance inclusion

In many cases, participants commented that without adequate one-to-one staff support, persons with disabilities cannot undertake individual activities in the community. Two schemes seek to overcome this difficulty and to contribute to building friendships between people with and without disabilities.

In **Ireland**, the Best Buddies programme, introduced from the US, helps to connect people with intellectual disabilities with their communities 'one friendship at a time'. Volunteers are matched with persons with intellectual disabilities, spending time with that person both in and out of their home. Family members highlighted that the scheme helped their relatives make friends.

In **Finland**, a local chapter of Inclusion Finland KVTL (*Kehitysvammaisten Tukiliitto ry)* coordinates a Friend Card (*Ystävänkortti*) scheme. It aims to increase opportunities for persons with intellectual disabilities to participate in leisure and cultural events and activities in the community with the support of a friend. A friend or support person gets free entry to activities such as the theatre, concerts, cinema, trips and different types of sports and cultural events, with a person with an intellectual disability. All persons with intellectual disabilities are entitled to a Friend Card.

For more information, see the Best Buddies website.

"[My brother] had [a 'Best Buddy'] and I thought that was so effective. [The 'buddy'] came and sort of brought [my brother] places that [my brother] was interested in. [My brother] loved machinery and [the 'buddy' would] bring him out to the bog to the tractor and look at the turf being cut and he was in his element." (Ireland, family member of a person with disabilities)

Barrier 2: Unavailable or inaccessible general services

"For me, well for the people, in my opinion, it means an individual approach with respect to the living conditions, so no standardised services in large facilities, but custom-fit living conditions for each individual client, what he/she needs, be it social services or employment or different kinds of support and compensations [...]. So that they would not be in a large facility in which the individuality dissolves." (Slovakia, representative of national human rights body)

Achieving independent living also means that people with disabilities can access and use the services available to the general public on an equal basis, as set out in Article 19(c) of the CRPD. Where these services exist, these they are crucial sources not only of support but as a means to participate in community life. Persons with disabilities participating in the research in Italy, for example, mentioned transport and health assistance as services they commonly use, indicating that these services become reference points in their daily lives.

"You can move out into normal society but societies are not ready for people to live in. Basically from the transport service to accepting people into the workforce and suitable accommodation [...], lots of things [are] not suitable to integrate people with disabilities as equal members of society." (Ireland, person with a physical disability)

However, the research reinforces previous FRA evidence by indicating that such services are often not accessible to persons with disabilities or unresponsive to their needs.[78] Participants mentioned barriers to deinstitutionalisation associated with issues concerning three types of service in particular:

- housing,
- healthcare, and
- transport.

Section 3.5.6. covers access to employment services. Participants emphasised that being unable to access these services, and facing discrimination and prejudice when trying to do so, deepens people with disabilities' isolation and their families' sense of helplessness.

---

[78] FRA (2017), *From institutions to community living: Part III: outcomes for persons with disabilities*, Luxembourg, Publications Office; FRA (2012), *Choice and control: the right to independent living*, Luxembourg, Publications Office.

Surveys show barriers to accessing everyday services persist

To assess to what extent community services and facilities for the general population are available to people with disabilities, FRA analysed data from existing EU-wide statistical surveys, namely the European Statistics on Income and Living Conditions (EU-SILC). The results are published in the FRA report *From institutions to community living - Part III: outcomes for persons with disabilities*.

The analysis shows that, on average, 43 % of persons with disabilities in the EU have difficulties in using at least one of five common types of everyday services – grocery shopping, banking, postal, primary healthcare and transport services – compared with 33 % of persons without disabilities. People with disabilities most often face difficulties accessing public transport services (26 %, compared to 19 % of persons without disabilities), postal services (25 %, compared to 18 % of persons without disabilities) and primary healthcare services (23 %, compared to 16 % of persons without disabilities). Persons with disabilities living alone, and older persons with disabilities, are more likely to face difficulties accessing one or more of these services than younger persons with disabilities or those living with other people.

For more information, see: FRA (2017), From institutions to community living - Part III: outcomes for persons with disabilities*, Luxembourg, Publications Office.*

Securing housing in the community is often the central element in a deinstitutionalisation process, as it is through their living arrangement that people with disabilities access their main support services (see Section 3.5.3.). However, participants, particularly from DPOs, also raised the importance of people with disabilities being able to access regular housing on an equal basis with others. In practice, this is impeded by a lack of accessible social housing. In Bulgaria, for example, participants with physical disabilities explained how a lack of affordable and accessible social housing prevents them from living outside residential services. They reported having to spend their own money to adapt social housing to their needs, and criticised local authorities for not recognising the need to make more accessible housing options available.

A similar picture emerges in Ireland. Official policy states that housing for people with disabilities should be provided by local authorities, as for anyone else with a housing need.[79] However, many participants felt that local authorities do not fully take into account the needs of people with disabilities in terms of accessibility and suitable locations. This left them feeling that houses owned either by service providers or the Health Service Executive (HSE) are in fact a better option, despite them being tied to particular support.

Housing solutions in Finland

In Finland, there are blocks of flats with rental apartments where both persons with and without disabilities live together. One such block in the case study locality accommodates 15 residents with intellectual disabilities and 21 persons without a disability, for example. Services for persons with disabilities with different levels of support needs are provided in the block.

Participants felt that this type of housing provides a balance between independence and preventing loneliness for persons with intellectual disabilities. They noted that it may also foster independence of adult children with disabilities and reduce the burden on ageing parents. A representative of a disabled persons' organisation and a resident of the unit mentioned a case where the parent and their daughter with an intellectual disability moved into the same building, but in different apartments. They considered this a good practice and a successful example of maintaining independence on both sides, while keeping the distance close enough for any need of support.

Participants also highlighted such apartment blocks as helping to promote interaction and understanding between persons with and without disabilities. One participant living in such a block commented:

"Somehow it's probably quite easy to create trust between [people with disabilities] and the [other] tenants. If I was a family member I would think it is easy in a place like this where there's staff to trust the other tenants easier and quicker as well compared to a strange apartment building where they live alone and no one knows them." (Finland, member of the local community)

However, such arrangements may raise questions about the choice and control they afford persons with disabilities in practice, particularly if services for persons with disabilities are linked to living in these apartment blocks. The concentration of persons with disabilities living close together could also constitute "satellite" living arrangements, which the CRPD Committee has criticised as appearing to be individual living but, in practice, revolving around institutional practices.

---

[79] Ireland, HSE (2016), *Supporting People with Disabilities to access appropriate housing in the community: A guidance document developed by the housing work stream of the Time to Move On (from Congregated Settings) subgroup under the Transforming Lives programme.*

Many participants, particularly staff and families of persons with disabilities, outlined difficulties in accessing healthcare services. In addition to availability and accessibility, they reported problems associated with prejudice and discrimination. In Bulgaria, for example, social assistance officials criticised healthcare providers and their emergency units for often refusing to treat people with disabilities. Family members also spoke about doctors requiring that people with mobility issues travel to health centres for appointments. As relatives have no access to suitable transportation, the person is deprived of health services.

Participants also reported that people with disabilities' physical and mental health problems are underplayed or ignored. This reinforces the findings of FRA's report *Choice and control: the right to independent living*, which highlighted that medical staff attribute any health difficulty to a person's impairment. One family member in Ireland recounted how, when her non-verbal sister went to hospital, staff maintained that her symptoms were a progression of her impairment. She believes her sister would have been sent home to die had the family not insisted on more tests. These identified an infected wisdom tooth as the source of the problem. Participants in Finland expressed concern that in-home healthcare services are being scaled back and their quality diminishing.

Difficulties accessing general health services left some participants feeling that institutions present a better option for people with significant medical needs. Staff participants sometimes highlighted easy access to appropriate healthcare as one of the advantages of institutional settings.

"Everything was so easy in the institution. Everything worked. There was a medical doctor, all kinds of therapists, and everything worked so well there." (Finland, employee training persons with disabilities undergoing deinstitutionalisation)

Finally, participants spoke about the inaccessibility of the physical environment, in particular public transport. Both are 'gateway' services, as accessible towns and cities facilitate access to other services and activities in the community, ranging from reaching jobs, to attending cultural events and meeting up with friends and family.

"[People in wheelchairs] must struggle with bad pavements all over Slovakia, bad roads, bad bus stops. And [some people] even laugh at them because they don't communicate with people in wheelchairs like they would communicate with me, but they mock them for not having their legs or for having bad legs."(Slovakia, person with a disability)

Where public transport is not accessible, many people with disabilities rely on specialised transport services. However, some participants worried that budget cuts will reduce the availability of such services. One participant in Finland was anxious that this would further isolate persons with intellectual disabilities from their communities.

Barrier 3: Inflexible rules and regulations on the provision of services to people with disabilities

Where services in the community exist, some participants – particularly service providers at the local level – felt that they were subject to excessive and inflexible rules and regulations. Although often imposed in an effort to increase standards, many practitioners instead viewed these standards as undermining their potential to deliver services that facilitate 'ordinary' lives in the community.

This perception often concerned rules regulating housing. As housing for persons with disabilities is typically regarded as part of a package with support for living in the community, it is often regulated in a similar manner to institutional services. This can result in a less than homelike atmosphere. In Slovakia**,** for example, regulations stipulate what participants viewed as unrealistic hygiene standards for supported living flats. In Ireland, the requirement to indicate fire exits, and display complaints procedures, staff lists and menus were seen as contributing to an institutional atmosphere. Participants felt that this reflected an emphasis on 'tick-box' procedures rather than a true measure of quality of support.

"It's important to invest in connecting people who are motivated to want to do this with people who have mileage on the clock actually doing it rather than generating elaborate documentation, promoted prescriptively, by people who haven't done it. Signal and promote common objectives but allow teams to evolve their own procedures and processes." (Ireland, employee of an institutional service)

Participants also feared that inflexible legislation and regulations could lead to innovative housing options being rejected for not meeting particular criteria. They felt that these criteria are sometimes out of date or overly rigid, and not conducive to producing individualised services. Some participants in Italy, for example, worried that local authorities' focus on complying with restrictive legal requirements when choosing which projects to support could impede their potential to identify and develop new approaches.

"What I see now is [the] Ministry of Social Affairs, together with the Finance Ministry devising some sort of standards – for this service this, for the other service that […] But within the service, what are the cases, what are the [support needs], nobody is looking at this at all. Do you understand, each service has some specificities - ask these service providers what they need, motivate them, let them say 'I need this, and this and this' and do not impose these standards all over Bulgaria for all services." (Bulgaria, manager of a community-based service)

Many practitioners attributed these problems to a lack of practical knowledge and experience among the national policymakers responsible for devising the rules and regulations. In place of rigid regulations, they suggested that higher quality outcomes could be achieved by directly engaging with service providers. One staff member from Ireland, for example, called for the regulator of disability services to have a proactive advisory role in addition to its existing inspection-focused mandate.

"Instead of an inspection though, [the regulator] should come out and… give you some advice first. [They] should be there in an advisory role or you should have somebody in your area [you could turn to], saying 'Look, we're going to set up this innovative service, we want to trim it down a bit, help us out'". (Ireland, employee of service providing institutional and community-based services)

In contrast, where housing and the provision of support are separately organised, there is potential for gaps in oversight and accountability. One service provider in Ireland has developed a model of providing support that is distinct from housing arrangements and therefore not under the remit of the regulator of disability services. Some Irish participants felt this is a distinct advantage as it avoids institution-like standards. However, national-level participants were concerned that no oversight measures were place to fill that gap.

Barrier 4: Lack of employment opportunities for persons with disabilities

Having a job is a crucial determinant of identity and social standing. Participants underlined that it provides self-confidence and independence, as well as the opportunity for interaction with colleagues and the wider community for people leaving institutions. Employment also offers the prospect of financial security, crucial for persons with disabilities who often face additional costs relating to their impairment.

FRA evidence consistently shows, however, that people with disabilities face numerous obstacles to accessing employment on the open labour market.[80] This exacerbates the lack of opportunities for employment as a result of the financial and economic crisis. Participants in this research reiterated all of these challenges, highlighting difficulties associated with:

- **Stigma and discrimination**: Persons with disabilities often face discrimination when looking for, and doing, their job. This is particularly problematic for persons with intellectual and psychosocial disabilities, participants in Italy felt. Two Irish stakeholders who employ service users with disabilities noted that clients sometimes distrust people with disabilities.
- **Loss of disability benefits**: Disability benefits are typically tied to income, meaning that the amount of financial assistance received begins to drop once people with disabilities start earning a salary. Many participants highlighted that this process begins very quickly, undermining the financial incentive to work and creating a so-called 'welfare to work' trap. In Ireland, this presents a particular challenge for those moving from institutions to their own apartments or houses, as the rental supplements they receive do not usually cover actual rental costs.
- **Qualifications:** Persons with disabilities, particularly those not educated in mainstream schools, often lack the formal qualifications necessary for many jobs.
- **Support at work:** Limited resources often mean that staff cannot support services users at work. However, several employers in Ireland felt that their employees with disabilities tend to do better when their support staff are not present.

Government employment programmes seek to create employment opportunities for persons with disabilities.[81] However, participants identified several weaknesses that reduce the effectiveness of these initiatives. Participants with physical disabilities in Bulgaria criticised national authorities for not consulting them when developing subsidised employment programmes. They felt that this had resulted in issues concerning job options and remuneration, as well as the sustainability of the jobs available.

"I am angry because we have an Agency for the people with disabilities, we have an Employment Agency and we have no adequate programme. This is terrifying." (Bulgaria, director of a community-based service)

In many cases, however, employment opportunities for persons with disabilities in all five countries remain concentrated in so-called sheltered employment

---

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

[81] See, for example, the Academic Network of European Disability Experts' country reports on employment.

schemes, outside the open labour market. The CRPD Committee has criticised such programmes for segregating persons with disabilities.[82] Participants had opposing views about these schemes. In Bulgaria, local policymakers, employment authorities and social service managers viewed the slow development of sheltered employment as a barrier to the deinstitutionalisation process. However, DPOs insisted that such programmes confirm and reproduce institutional models of service provision, and keep people with disabilities isolated from the community.

Barrier 5: Staff working conditions

"[What will make deinstitutionalisation a reality is a] sufficient number of educated, competent, content, devoted and duly remunerated employees." (Slovakia, employee of an institutional service)

Staff of disability services, whether institutional or community-based, have a crucial role in implementing deinstitutionalisation. One factor that participants felt undermined their enthusiasm for the process is concern that it might result in less favourable working conditions. At the general level, trades unions representing care staff have advocated against deinstitutionalisation, expressing concern that individualised services for persons with disabilities might result in privatisation of social care and a liberalisation of working conditions for the social care workforce.[83]

Participants in this research focused on their direct experience of the impact of deinstitutionalisation on different aspects of the working conditions of staff:

- **Recruitment:** In Bulgaria, participants reported difficulties recruiting staff to work in social care services. This can leave managers with little option but to take on staff members who previously worked in institutional services, sometimes without any re-training, with the risk that this results in institutional practices being transferred into the community. Asked about how staff react to the deinstitutionalisation process and whether they ask questions about the strategy and its implementation, the director of an institution replied that they show little concern because they are mostly pensioners, and that recruiting people to work in small group homes is "a massive problem" (see highlighted quote for full comment).
- **Retention:** Other participants highlighted that the heavy demands placed on staff resulted in high turnover rates. They noted a lack of support to prevent issues such as burnout.
- **Remuneration:** Some staff highlighted that providing support in the community tends to be less well paid. For example, staff spending the night in community-based services may be able to sleep rather than be awake all night, as in institutional settings, and are therefore paid at a lower rate. In addition, as support provided in community-based services does not involve the administration of medical treatment, as is often the case in institutions, it is classified as lower-skilled work.
- **Working hours:** Others highlighted that working in community-based settings may involve tasks beyond regular working hours. One staff member in Ireland said that she accompanied a service user on holiday "because I like the woman that I support", despite not being paid for all the hours she worked.
- **Continuity and stability of employment:** Some staff reported that work in community-based services meant they are expected to move between different services more regularly. This made it harder to build up close relationships with service users. Several staff whose clients were about to undergo deinstitutionalisation worried that this would mean being separated from individuals they had supported for many years.

"They [staff confronted with the deinstitutionalisation process] are absolutely not concerned about it, because 99% of them are pensioners. No young person wants to work there. [...] Currently, there is a massive problem in recruiting people to work in [the small group homes], everywhere. [...] nobody wants to work there. It will be the same for the small group homes for adults. [...] [T]he qualified people from the institutions were taken to work in small group homes. With us were left those who cannot cope. We cannot lie about this." (Bulgaria, director of an institutional service)

Finally, some staff recognised that there can be a tension between what is good for the service user and what is good for the staff.

"The less hours we have with them the more they were growing independent. Which was terrible for us but better for them. So, the less they needed us, the more they went on, the better for themselves. And then we were shifted on to the next [person]." (Ireland, employee of a community-based service)

---

[82] See, for example: CRPD Committee (2018), *Concluding observations on the initial report of Slovenia*, CRPD/C/SVN/CO/1, April 2018, para. 45; CRPD Committee (2018), *Concluding observations on the initial report of Luxembourg*, CRPD/C/LUX/CO/1, October 2017, para. 46.

[83] European Foundation for the Improvement of Living and Working Conditions (Eurofound) (2006), *Employment in social care in Europe*, Dublin, Publications Office.

3.6. Cross-cutting issues

Research consistently shows that there are stark differences in progress towards deinstitutionalisation for different groups of people with disabilities. To explore these issues in more depth, participants were asked about their views on the impact of different types and degrees of impairment, and the role of age in the deinstitutionalisation process.

Impact of different types and degrees of impairment on the deinstitutionalisation process

Like the convention as a whole, Article 19 of the CRPD applies to all persons with disabilities, irrespective of the type or severity of their impairment. Previous FRA research has, however, shown that disability services struggle to respond to the needs of persons with intellectual and psychosocial disabilities, as well as those with more severe impairments.[84] This is reflected in the data on people with disabilities living in institutions: these groups of persons with disabilities are disproportionately likely to be institutionalised.[85] Indeed, in Finland, Italy and Ireland, the deinstitutionalisation process largely concerns people with intellectual disabilities, as people with other types of impairment typically live in the community.

This research reveals a high level of consensus that both the type and degree of impairment have a significant impact on the deinstitutionalisation process. Participants indicated that achieving deinstitutionalisation for people with intellectual and psychosocial disabilities, and those with complex needs, presents a greater challenge than for other groups of persons with disabilities. This may indicate residual stigma towards these groups, even among stakeholders who feel themselves to be strongly supportive of deinstitutionalisation and independent living principles.

Several participants reflected on the consequences of such attitudes, noting that the transition process usually starts with those with less severe impairments and lower support needs.

"So, what happens is the people with the higher needs are left and left and left and left." (Ireland, employee of a service providing institutional and community-based services)

Others acknowledged that they run counter to a rights-based approach to disability.

"I wonder if [...] actually we believe that only some people can [are able] and therefore have the right to leave independent lives, and another part are too disabled, for us to think that they could ever be somewhat more independent." (Bulgaria, director of a community-based service)

Participants gave various reasons for why they felt achieving deinstitutionalisation for certain groups of persons with disabilities is more challenging. Stigma and discrimination are a common theme of these explanations.

Several participants pointed to stereotypes about people with intellectual and psychosocial disabilities within society as a whole, which make communities less receptive.

"In the region where I come from, [the people's attitude] is a disaster. When they learn that you are mentally ill, you are done with your life. They give you no chance in life, absolutely none." (Slovakia, person with a psychosocial disability)

"Three years ago [...], since we had to create a project of supported housing, we had to go to every estate agency in [the town]. In [the town] there are 3,000 empty flats. [...] [But] every time we said that it was for mental health, the flat was not available anymore. We searched for one and a half years on the real estate market because no one wanted to rent us a flat, simply because there were mental health issues." (Italy, employee of a community-based service)

In other, cases, however, the research suggests that stakeholders in the transition process themselves felt that deinstitutionalisation is not appropriate or achievable for all persons with disabilities. A significant number of participants, particularly at local level, did not support deinstitutionalisation for people with the most severe intellectual impairments.

"It's obvious that it is impossible to do this for everyone. I mean there are some situations where the institutional or semi-institutional solution remains the most appropriate one." (Italy, local policymaker)

In some cases this seemed to reflect concern that the lack of community-based services means that specialised services for these groups of persons with disabilities are only available in institutional settings. In others, participants cited concerns about the cost of individualised 24-hour staff support or the difficulty

---

[84] FRA (2015), *Violence against children with disabilities: legislation, policies and programmes in the EU*, Publications office, Luxembourg; FRA (2012), *Choice and control: the right to independent living*, Publications office, Luxembourg.

[85] Mansell, J., Knapp, M., Beadle-Brown, J. and Beecham, J. (2007), *Deinstitutionalisation and community living – outcomes and costs: report of a European Study*. Volume 2: Main Report. Canterbury: Tizard Centre, University of Kent.

of ensuring a truly self-determined process for people who are, for example, non-verbal.

Nevertheless, some responses suggested participants believed that moving people with the most severe disabilities to community settings would not result in meaningful change to their lives. This contradicts testimony from other stakeholders that people with severe impairments often benefit the most from deinstitutionalisation (see Section 2.2.2.).

"The employees have such a sceptical view [of deinstitutionalisation for people with severe disabilities]. [They think that] we would only move them from one bed to another. Like that. And what will we change by moving them? After all, they won't be doing anything, they will only be lying down all the time, in that room again. They could stay like this in the institution." (Slovakia, employee of an institutional service)

It is notable that, in many instances, persons with disabilities themselves had internalised this narrative and saw deinstitutionalisation as a 'reward' for those with lower support needs and not as a human right. In Slovakia, for example, participants with disabilities often referred to those with less severe intellectual disabilities as 'the capable ones', able to undertake the deinstitutionalisation process. This may be linked to the relative lack of self-advocacy organisations among these groups. In Bulgaria, where significant numbers of people with sensory and physical disabilities live in institutions, representative organisations indicate that people with these impairments are more likely to join the independent living movement than those with psychosocial and intellectual disabilities.

Impact of age on the deinstitutionalisation process

The impact of age on the deinstitutionalisation process was a recurring theme in the research at both ends of the age spectrum. In three of the countries covered by the research – Finland, Ireland and Italy – the majority of those living in institutions are older persons, as younger people do not generally enter institutions.

Many participants across the five countries expressed reservations about deinstitutionalisation for older people. Some worried about how someone who has spent all of their life in an institution will fare in the transition to community living. In Finland, for example, local practitioners felt that the institution has become these people's 'home' and that requiring them to move out would not necessarily be a humane solution. Participants in Italy emphasised that any deinstitutionalisation of an older person would need to be a gradual process. They gave the example of older people with severe intellectual impairments for whom, in their view, in-home support would be difficult, suggesting they could have access to a range of activities during the day, but return to the institution at night.

Others highlighted the lack of suitable alternatives in the community. In Bulgaria, the lack of community-based services means that participants often construed deinstitutionalisation as a return to family support (see Section 3.2.6.). This was perceived as a barrier for older people, who may not have relatives willing or able to support them.

"[T]hose who remain in our institution are over 60 years old, they have no relatives to support them. We cannot provide them with support outside." (Bulgaria, director of an institutional service)

Others mentioned the trend in some countries for older persons to move into long-term care,[86] whether or not they have an impairment. In Ireland, where most participants in positions of authority expressed their commitment to deinstitutionalisation for all, a couple made an exception for older people.

"The only people that it's probably not for are the very aging population who in a natural environment may well end up in a nursing home type environment anyway because that's the natural progression." (Ireland, local official)

Participants gave a more positive overall picture of the role of younger age. Younger adults with disabilities, particularly those who have been educated in mainstream schools, often act as drivers for deinstitutionalisation (see Section 3.1.4.).

However, here too, a lack of community-based services presents a problem for young adults with disabilities who wish to leave the family home and live independently in the community. In Bulgaria, benefits for the families of children with disabilities stop abruptly when the child turns 18. This often leaves them feeling they have no choice but to join a long waiting list for a place in an adult institution. In Slovakia, large numbers of children remain in institutional homes with little alternative than to move from there to an institution for adults with disabilities.

"When they are 18, they go from [children's homes] to institutions. In [children's homes], they at least care somehow, do something with them, and then it all gets killed in social services institutions." (Slovakia, representative of a non-governmental organisation)

---

[86] European Network of National Human Rights Institutions (2017), *"We have the same rights" The Human Rights of Older Persons in Long-term Care in Europe*.

PAM'S STORY — IRELAND

HUMAN STORY

Pam came to the congregated setting when she was a teenager. She suffers from epilepsy and it seems that her severe intellectual and physical disability is largely acquired. She recounts that, when she was a child, she saved her granny from falling into the fire (and asks for this to be included in her personal story). Now, however, she cannot move independently and has issues around swallowing and eating. She speaks with difficulty and can be hard to understand. Despite this, she has a bright, engaging personality and is not afraid to speak her mind.

She recounts her experiences in [the congregated setting] with less inhibition than some other service users. "You won't believe what I will tell you." she says, describing the conditions in [the congregated setting]. At first, she was in the main house. There, the beds were all right next to each other, with personal space delineated just by a small locker for personal effects, like in a dorm room. Later, she was moved to another unit, where the doors were locked to prevent service users from wandering. She describes an act of aggression by another service user: "I was kicked in the stomach by [service user]." She remembers the food with particular distaste: "It was always porridge for breakfast, always", she says. "Could you ask for anything else?" I ask. "No". "Why not?" "You wouldn't have been given it!"

She moved from the congregated setting to her current home in May 2013. She was among the last in her particular unit, which was closing, to undergo deinstitutionalisation. "When they told me I was moving out, I was overjoyed", she says. She lives with two other service users: [Emily], who has Down's syndrome and is non-verbal, and [Catherine], who has clear but limited speech. The housemates seem happy spending time together, but also have enough space to spend time alone. They each have their own bedroom and there are two sitting rooms in the large bungalow. "It is terrific, I have my own freedom", says Pam.

She describes in detail what she likes to eat – the support worker explains that they ask each service user at each meal what they feel like eating, because they all have issues around swallowing. She enjoys welcoming guests to the house – when the neighbour calls over, she tells me, she says: "Come in, Mr [Corcoran]."

When asked if there is anything she misses about the congregated setting, she says emphatically: "Not at all. [The congregated setting] was nobody's favourite."

Key drivers and barriers of the deinstitutionalisation process: national and group perspectives

Why this survey?

A central aim of the research was to explore what different stakeholders view as the most important drivers and barriers of deinstitutionalisation. To complement and verify the evidence gathered from the interviews and focus groups, FRA implemented an online survey. Respondents were predominantly those who had already participated in the research. More information on the survey methodology is available in Annex 2; the accompanying technical report presents a more detailed analysis of the results.[87]

In the first round of the survey, 249 stakeholders participated. This dropped to 150 participants in the second round. In particular, only a small number of persons with disabilities and their family members participated in the second round, meaning these results should be treated with caution.

What do the results show?

As well as confirming the overall results of the project, the survey results highlight differences in perceptions and views between stakeholder groups and countries.

The first round of the survey asked participants to rank the key features of deinstitutionalisation in order of importance. The results show a clear split between stakeholders with a more 'official role' in the deinstitutionalisation process and those experiencing it in a personal capacity:

- Overall, commitment and change in attitudes emerged as the two most important features, ahead of active cooperation between the different actors involved in the deinstitutionalisation process. Practical organisation and guidance were seen as relatively less important, perhaps indicating that participants viewed them as having more of a 'supporting role'.
- Public authorities on the national and local level, as well as managers and staff of institutions and community-based services ranked 'commitment to deinstitutionalisation' as the most important feature. Change in attitudes and active cooperation were the next most important features for these groups.
- For persons with disabilities and their families, DPOs and advocacy organisations, 'change in attitudes' was the most important feature. For these groups, commitment was the second most important feature.
- Persons with disabilities identified provision of guidance throughout the process as more important than other respondent groups.

Table 5: Ranking of key features of a successful deinstitutionalisation process, by respondent group, across the five countries

Overall ranking	Persons with disabilities	Family members/ carers	DPOs/ Self-advocates	Public authorities - local, regional	Public authorities - national	Managers/ staff of institutions	Managers/ staff of community-based services
Commitment	Change in attitudes	Change in attitudes	Change in attitudes	Commitment	Commitment	Commitment	Commitment
Change in attitudes	Commitment	Commitment	Commitment	Active cooperation	Change in attitudes	Active cooperation	Change in attitudes
Active cooperation	Guidance	Active cooperation	Active cooperation	Change in attitudes	Active cooperation	Change in attitudes	Active cooperation
Practical organisation	Active cooperation	Practical organisation	Practical organisation	Guidance	Practical organisation	Practical organisation	Guidance
Guidance	Practical organisation	Guidance	Guidance	Practical organisation	Guidance	Guidance	Practical organisation
Number of participants	*30*	*22*	*47*	*41*	*34*	*33*	*42*

Note: This ranking is based on a score board. A first place ranking is awarded 5 points, a second place ranking 4 points, etc. For each feature the mean score is the sum of the total points received, divided by the number of respondents. The features are then ranked according to this mean. Where two features appear in one cell, they were ranked of equal importance by participants.

Source: FRA, 2018

---

[87] For more information on FRA's Delphi process, see the background document available on FRA's website.

The picture at the country level is largely similar. With the exception of Slovakia, participants in all countries ranked 'commitment' as the most important feature, followed by 'change in attitudes" and "active cooperation'. In Slovakia, this order was reversed, with change in attitudes in first place. Practical organisation and guidance were ranked among the least important features in all countries.

Table 6: Ranking of the key features of a successful deinstitutionalisation process by country

Overall ranking	Bulgaria	Finland	Ireland	Italy	Slovakia
Commitment	Commitment Change in attitudes	Commitment	Commitment	Commitment	Change in attitudes
Change in attitudes		Change in attitudes Active cooperation	Change in attitudes Active cooperation	Change in attitudes Active cooperation	Commitment Active cooperation
Active cooperation	Active cooperation Practical organisation Guidance				
Practical organisation		Guidance	Practical organisation	Practical organisation	Guidance
Guidance		Practical organisation	Guidance	Guidance	Practical organisation
Number of participants	*50*	*63*	*44*	*36*	*56*

Note: *This ranking is based on a score board. A first place ranking is awarded 5 points, a second place ranking 4 points, etc. For each feature the mean score is the sum of the total points received, divided by the number of respondents. The features are then ranked according to this mean. Where two features appear in one cell, they were ranked of equal importance by participants.*

Source: *FRA, 2018*

Turning to individual drivers and barriers, the survey helps to indicate which elements participants viewed as particularly important. The first round of the survey asked participants to rate the importance of a number of drivers and barriers under each feature. In the second round, participants were given the two drivers and two barriers under each feature that were perceived as most important, and asked to rank them in accordance of importance.

Tables 7 and 8 show the results of this ranking. Among the drivers, participants viewed support for persons with disabilities throughout the deinstitutionalisation process, and coordination between actors from different sectors at the local level as most important.

Exploring the results in more depth shows some notable differences in the importance attached to certain drivers by different respondent groups.

- Although support for persons with disabilities throughout the deinstitutionalisation process and cooperation between actors from different sectors at the local level were ranked the most important drivers overall, persons with disabilities themselves only ranked these sixth and fifth of the ten most important drivers, respectively.
- Positive portrayals of people with disabilities in the media was ranked tenth among these drivers overall. However, persons with disabilities and in particular family members and carers viewed this as more important than other respondent groups.
- Availability of support services for persons with disabilities in the community ranked as third most important driver overall. Local and regional public authorities ranked it only eighth most important, however.
- Practical guidance on deinstitutionalisation for different groups of actors involved in the process ranked seventh overall, but came in second place among managers and staff of institutions.

Table 7: Ranking of the most important 10 drivers, by respondent group, across the five countries

Drivers	Overall Rank	Persons with disabilities	Family members/carers	DPOs/Self-advocates	Public authorities - local, regional	Public authorities - national	Managers and staff of institutions	Managers and staff of community-based services
Persons with disabilities receive support throughout the deinstitutionalisation process	1=	6	1=	1	4	1	5	1=
Actors from different sectors at the local level coordinate their activities	1=	5	1=	4	1=	5=	1	1=
Availability of support services for persons with disabilities in the community	3	3	3	2=	8	3	4	3=
Actors at the local level push for deinstitutionalisation	4=	4	6	5=	5	8	8	5
Empowerment of persons with disabilities	4=	10	8	2=	6	2	6=	7
Involvement of families of persons with disabilities throughout the deinstitutionalisation process	4=	9	3	7=	1=	5=	2=	3=
Staff working with persons with disabilities get training on deinstitutionalisation	7=	2	9=	9	1=	4	6=	8
Practical guidance on deinstitutionalisation for different groups of actors involved in the process	7=	1	6	7=	7	9	2=	6
Measures to build up people with disabilities' self-advocacy skills	9	7=	9=	5=	9	7	9	9
The media portrays positive images of persons with disabilities	10	7=	5	10	10	10	10	10

Note: *This ranking is based on a score board. A first place ranking is awarded 10 points, a second place ranking 9 points, etc. For each driver the mean score is the sum of the total points received, divided by the number of respondents. The drivers are then ranked according to this mean.*

Source: *FRA, 2018*

Among the barriers, insufficient preparation for deinstitutionalisation, both at the national and at the local and regional level emerged as the most important barriers. Again there were some notable differences in the views of different respondent groups, however:

- Managers and staff of institutions and community-based services, and local and regional public authorities, highlighted the lack of suitable housing for persons with disabilities available in the community as a particularly important barrier. It was ranked in seventh place by national officials, however.
- National public authorities ranked a persisting institutional culture in community-based services as the most important driver. In contrast, managers and staff of institutions, and managers and staff of community-based services, ranked it in eighth and ninth place, respectively.
- A lack of involvement of people at the local level in national deinstitutionalisation planning was ranked as the ninth most important barrier overall, but was in second place among persons with disabilities and their family members and carers. Similarly, participants ranked a lack of employment opportunities tenth overall. However, this was the third most important barrier for persons with disabilities.
- In contrast, strongly embedded care models among service providers was ranked in tenth place by persons with disabilities and family members and carers, but was in fifth place overall and first place among respondents from disabled persons organisations. Participants with disabilities also rated insufficient or difficult to access funding to support deinstitutionalisation as more important (first place) than other participants (seventh overall).

Table 8: Ranking of the 10 most important barriers, by respondent group, across the five countries

Barriers	Overall Rank	Persons with disabilities	Family members /carers	DPOs/Self-advocates	Public authorities - local, regional	Public authorities - national	Managers and staff of institutions	Managers and staff of community-based services
Insufficient preparation for deinstitutionalisation at the local and regional level	1=	3=	4=	4=	1	2=	3	4
Insufficient preparation for deinstitutionalisation at the national level	1=	5	2=	4=	2=	5	2	2=
Limited commitment to deinstitutionalisation at the local or regional level	3=	7	1	3	5=	2=	5=	2=
Lack of suitable housing available in the community for persons with disabilities	3=	8	4=	6	2=	7=	1	1
Strongly embedded care models among service providers	5	10	10	1	4	2=	5=	6=
Institutional culture persists in community-based services-	6	9	7	2	5=	1	8	9
Insufficient or difficult to access funding to support the deinstitutionalisation process	7	1	4=	8	7=	6	5=	5
Persons with disabilities and their families do not receive adequate information about the deinstitutionalisation process	8	6	8	7	7=	7=	4	6=
National planning of deinstitutionalisation does not involve people at the local level	9	2	2=	10	9	9	9	8
Too few employment opportunities for persons with disabilities	10	3=	9	9	10	10	10	10

Note: *This ranking is based on a score board. A first place ranking is awarded 10 points, a second place ranking 9 points, etc. For each barrier the mean score is the sum of the total points received, divided by the number of respondents. The barriers are then ranked according to this mean.*

Source: *FRA, 2018*

4

Measures to achieve successful deinstitutionalisation

Identifying the drivers of and barriers to deinstitutionalisation is only the first step in supporting successful transition processes. Turning this knowledge into concrete actions requires identifying those measures that can capture and strengthen the drivers, and minimise and overcome the barriers.

At each stage of the research, participants were asked what is needed to make deinstitutionalisation a reality. Their responses reflected the extent of progress to date in their particular area. Nevertheless the consistency of proposed objectives and measures – whether already in place or that should be introduced – across countries and across stakeholder groups is striking.

This section examines some of the measures suggested by participants with regard to each of the five essential features of deinstitutionalisation identified in the research. Many of these relate directly to the steps to ensure full implementation of the right to independent living set out by the CRPD Committee in its General Comment on Article 19 of the convention.[88]

4.1. Commitment to deinstitutionalisation

"States parties should [...] adopt clear and targeted strategies for deinstitutionalisation, with specific time frames and adequate budgets, in order to eliminate all forms of institutionalisation of persons with disabilities; special attention should be paid to persons with psychosocial and/or intellectual disabilities and children with disabilities currently in institutions"
CRPD Committee (2017), General comment No. 5 (2017) on living independently and being included in the community, CRPD/C/GC/5, 27 October 2017, para. 97 (g)

The General Comment on Article 19 of the CRPD sets out the wide range of legal and policy measures necessary to implement the right to independent living, from repealing laws preventing persons with disabilities choosing where and with whom to live, to providing empowerment training to support persons with disabilities to learn how to enforce their rights. Participants across countries and categories of research participants agreed that commitment is a crucial prerequisite of successful implementation of deinstitutionalisation. However, they were equally clear that laws and policies alone are insufficient. To support deinstitutionalisation in practice, commitment must be backed by**:**

- understanding of the human rights-based model of disability, and the specific rights guaranteed by the CRPD;
- appropriate legislation to implement it;
- adequate and properly allocated funding;
- a long-term perspective on deinstitutionalisation funding and policy;
- actions to empower persons with disabilities to claim their rights, in particular through their representative organisations.

---

[88] CRPD Committee (2017), General comment No. 5 (2017) on living independently and being included in the community, CRPD/C/GC/5, 27 October 2017.

The right to live independently and be included in the community underpins the deinstitutionalisation process. Yet understanding that it is a right for all is still lacking. Indeed, some stakeholders believe certain groups of people with disabilities are not 'suitable' for deinstitutionalisation. People with disabilities and their representative organisations often felt that knowledge and understanding of Article 19 is lacking among frontline staff, the general public and, sometimes, local and national officials. They underscored the importance of referencing the CRPD and using its terminology in their advocacy and campaigning as one way to address this knowledge gap.

"[The Convention] should stop any further debate about what is the right response. [...] Article 19 is the right response, Article 12 is the right response. So it's all there and it's supposed to be legally binding in all states." (Ireland, representative of a non-governmental organisation)

Fulfilling the rights set out in the CRPD requires legislative reform in all EU Member States, as both the CRPD Committee's concluding observations and FRA research show.[89] Participants highlighted the importance of legislation in two main areas. Firstly, legislation setting out the right of persons with disabilities to choose their place of residence and where and with whom they live on an equal basis with others provides the foundations for actions to implement deinstitutionalisation. Participants highlighted the importance of this legislation including measures to stop people entering institutions, as well as to provide a framework for leaving them.

Secondly, the closely related issue of appropriate supported decision-making structures empowers persons with disabilities to make decisions about their lives. However, the research shows that relevant legislation is either not yet in place, not fully implemented or not clearly understood by service providers. Participants felt that ensuring that persons with disabilities are no longer deprived of legal capacity, and instead supported appropriately to make their own decisions, is of vital importance. Such efforts should, they insisted, be given higher priority than is indicated by the lengthy delays in putting proposed provisions in place.

"If you are under guardianship, you have no right to anything! Now my deprivation is lifted and I have the right, as a free person, as a free citizen, to work things out by myself." (Bulgaria, person with disabilities)

Participants across the groups involved in this research felt that funding for deinstitutionalisation is insufficient. Too much money goes to institutions in their view, and not enough to independent living initiatives in the community; this should be reversed. They pointed to the need for more funding during the transition process, reflecting the additional cost of maintaining two parallel systems of institutions and community-based services. This, they argued, is particularly important at the beginning and end of a deinstitutionalisation process. ESIF can play a crucial role in covering these costs.

"So, [for some time you have to divide] available funds between both systems before the new system begins to work; [until then] you cannot close down the previous system, but you have to finance both before the new ones start to operate. And not even the EU structural funds envisaged that." (Slovakia, regional policymaker)

However, participants focused not only on the amount of funding, but how it can best be used. Participants in all countries and across stakeholder groups all stressed the need for individual needs based-assessments to channel available resources most effectively. These include schemes such as personal budgets and direct payments.

"To me, an ideal system of funding [...] is a personal budget that is some personal budget or benefits depending on the extent of the individual's dependence." (Slovakia, national policymaker)

Some participants also spoke about innovative forms of joint funding between the public, private and third sectors, as demonstrated by the use of social cooperatives (see promising practice box in Section 3.3.3.).

Concerning timeframes, participants reflected on how to balance the urgency of implementing deinstitutionalisation and the complexity of the task. While many deplored lengthy implementation delays and their effect on the lives of people living in institutions, others noted that deinstitutionalisation is a long and complicated process and needs to be got right rather than rushed.

"Developed European countries have done [deinstitutionalisation] in a period of 40-50 years. We are asked to do it in three, five or 10 years? If we need to close down institutions, we will close them, but the problems will remain. People are not going to live much better. We want to do it more smoothly, for it to be a really genuine process." (Bulgaria, national policymaker)

Finally, participants highlighted the importance of empowering persons with disabilities to enforce their rights under the CRPD. They noted that civil society organisations representing people with intellectual and psychosocial disabilities – who are most likely to be institutionalised – tend to be less well developed than

---

[89] FRA (2018), *Fundamental Rights Report 2018*, Luxembourg, Publications Office, Chapter 10. For more information, see previous *Fundamental Rights Reports; FRA (2015), Implementing the UN CRPD: An overview of legal reforms in EU Member States*, Luxembourg, Publications Office; and CRPD Committee's home page with concluding observations.

organisations of people with other types of impairment. Given the role of people with disabilities and advocacy organisations in driving deinstitutionalisation, they suggested that further empowering these actors will help to strengthen commitment to the process.

"Having champions for change is very important. Challenging people with disabilities to have high expectations of what is possible is very important." (Ireland, national policymaker)

4.2. A change in attitudes towards persons with disabilities

"Stereotypes, ableism and misconceptions that prevent persons with disabilities from living independently must be eradicated and a positive image of them and their contributions to society must be promoted. Awareness-raising should be provided for authorities, civil servants, professionals, the media, the general public and persons with disabilities and their families."

CRPD Committee (2017), General comment No. 5 (2017) on living independently and being included in the community, CRPD/C/GC/5, 27 October 2017, para. 77

Article 8 of the CRPD obliges State parties to sensitise society to the rights of persons with disabilities, and calls for the adoption of measures to combat stereotypes, prejudices and harmful practices. This includes, for example, effective public awareness campaigns, and "encouraging all organs of the media to portray persons with disabilities in a manner consistent with the purpose" of the convention. The general comment on Article 19 highlights the link between the two, highlighting that "awareness-raising is essential to create open, enabling and inclusive communities".[90] These changes in attitudes are also linked to how and where people with disabilities live. Congregated settings increase the likelihood that the community focuses on the trait linking the people living there – for example, having an impairment – rather than seeing them as individuals. Conversely, independent living arrangements are more likely to put the focus on the individual's personality and abilities.

"And of course, then you need not only authorities and representatives of DPOs, but as well experts by experience and the persons with disabilities, who can share their wishes and views." (Finland, national policymaker)

Participants generally felt that attitudes towards persons with disabilities are improving overall, but highlighted the need for additional measures to reinforce this trend. In addition, they highlighted the need for steps to further shift attitudes at a number of specific levels. All stakeholder groups stressed the importance of empowerment and self-determination of people with disabilities themselves as a key catalyst for attitudinal change among these actors:

- the general public;
- local communities where deinstitutionalisation is occurring; and
- people directly involved in the deinstitutionalisation process, including family members of people with disabilities and staff.

Awareness raising campaigns were highlighted as key in fighting stigma and 'fear of the unknown' concerning persons with disabilities among the general public. The media has a critical role in such campaigns, participants felt.

"We need many many promotion and awareness and campaigns. […] We also need to organise public demonstrations […] and use the media to be on the front line […] to make people understand […] that good practices exist. These simply need to be [brought to the awareness] of public officials who can then apply them." (Italy, national policymaker)

"If you ask me – awareness of the general public […] that these are people with some health problem, they need special care and attitude, but they are no different, to an extent, from all of us. […] So awareness of the population is also a big factor; one of the main factors to stimulate [deinstitutionalisation]." (Bulgaria, local official)

Participants suggested key elements of the content and focus of such campaigns:

- Participants across all countries and categories felt that positive stories of people with disabilities living independently contribute to changing the attitudes of the general population.
- Media and other communication channels should feature success stories of people with disabilities regaining choice and control over their lives. One community member emphasised that this should convey "an awareness of their abilities rather than disabilities".
- People with disabilities themselves should be at the forefront of all communication activities.

Turning to specific actors in the deinstitutionalisation process, participants called for more to be done to change attitudes among local communities. Such actions help to promote the inclusion of persons with disabilities in their new communities during and after deinstitutionalisation. Key to this is making persons with disabilities more visible in society. Many participants stressed that the best way to achieve this is through everyday interaction between persons with and

---

[90] CRPD Committee (2017), *General comment No. 5 (2017) on living independently and being included in the community*, CRPD/C/GC/5, 27 October 2017, para. 77.

without disabilities. Some suggested organising public information meetings and creating inter-sectoral teams to engage with various actors at the local level prior to people with disabilities moving into the community. Others spoke about more informal means, such as visiting new neighbours and using everyday services.

"The town has accepted them. [I remember] at the very beginning when we took all those wheelchairs outside… then we began to take our clients for walks around the town and everybody was giving us these stares, it was [not very pleasant], right? And now it is not [like that] anymore; now everybody takes it as a regular thing." (Slovakia, employee of an institutional service)

Participants also spoke about the importance of embedding positive attitudes among the families of persons with disabilities. Fear for their loved one's safety and, in some cases, overprotectiveness can prompt relatives of people with disabilities to be sceptical of deinstitutionalisation, hindering and blocking the process.

To overcome this, participants advocated engaging with families of people with disabilities early in the transition process and then keeping them informed and involved throughout. Self-advocacy and peer advocacy schemes for young adults could encourage this attitudinal shift. Once secured, family support is a valuable tool in efforts to change the attitudes of other actors.

"What is going to drive deinstitutionalisation is you have to catch the imagination of the families who will drive the political agenda as well, who will be on their local [members of parliament] saying 'I want this for my son or daughter." (Ireland, local official)

Discussions on changing the attitudes of frontline staff of institutions and community-based services focused on how to ensure that staff promote autonomy and inclusion, and do not fall back into more 'paternalistic' styles of support. Participants spoke about encouraging self-reflection and organising on-going human rights-based training and retraining.

"How do we guarantee that we're having a discussion with ourselves, we're having a discussion with the work community, so that we, the employees, don't create another kind of parallel culture next to the family culture. So that we're not the ones who decide." (Finland, employee of a community-based service)

Engaging persons with disabilities in processes of attitudinal change is crucial for their success, participants felt. Part of this is done through the involvement of disabled persons' organisations in awareness-raising campaigns, training initiatives and policy advocacy. However, participants noted that it also involves everyday efforts to build capacity for self-determination and to overcome learned dependence, giving persons with disabilities the confidence to advocate for their own rights.

"[W]e should say to a person with an [intellectual disability] 'what is it you want?' in order for them to tell us we have to be able to nurture them and develop that within them. We haven't done that, we have put them in an institution or a community group home with four others." (Ireland, local official)

"But then if you give them time and space, miracles happen. I've seen it personally. I've been like, do it, do it, I'll come back in a moment. Then it's like ta-da." (Finland, employee of a community-based service)

4.3. Active cooperation between the people involved in the deinstitutionalisation process

"[A] coordinated, cross-government approach which ensures reforms, budgets and appropriate changes of attitude at all levels and sectors of government, including local authorities, is required [for deinstitutionalisation]."
CRPD Committee (2017), *General comment No. 5 (2017) on living independently and being included in the community*, CRPD/C/GC/5, 27 October 2017, para. 58

Both the CRPD itself and the CRPD Committee address the question of vertical coordination between different levels of governance structures. Article 4(5) of the convention recalls that it "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, noting "undue fragmentation of policy" and calling for States parties to ensure authorities at all levels "are aware of the rights set out in the Convention and of their duty to effectively ensure the implementation of those rights".[91] In terms of horizontal cooperation across sectors, the OHCHR emphasises that support "should be based on effective coordination among health-care and social-service providers, and the housing sector".[92] Throughout the process, States parties must "ensure the participation of persons with disabilities, personally and through their representative organizations, in transforming support

---

[91] CRPD Committee (2013), *Concluding observations on the initial report of Austria*, CRPD/C/AUT/CO/1, September 2013, para. 10; and CRPD Committee (2015), *Concluding observations on the initial report of Germany*, CRPD/C/DEU/CO/1, May 2015, para. 6.

[92] UN 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. 26.

services and communities".[93] The measures participants proposed to enhance cooperation between the different actors involved in deinstitutionalisation address each of these elements.

Participants across the five countries highlighted the need for better cooperation and coordination between national, regional and local authorities, echoing recommendations stemming from FRA's reports *From institutions to community living*.[94] Measures to foster closer cooperation and ensure the engagement of all actors are required throughout the process, they felt, from public consultations and drafting of legislation and policies through to the implementation of the transition process. Responsibility for enhancing coordination is shared by all stakeholders, participants noted. Actors at all levels should proactively seek opportunities for more active engagement – from the top down by national level stakeholders, and from the bottom up by regional and local policymakers and service providers.

"We are used to working with laws, with decrees. [...] We will cooperate if someone orders us to do so but if it comes to initiative and creativity, it is very difficult." (Bulgaria, local official)

Participants drew on concrete examples to identify how to improve cooperation across sectors. Some called for an integrated approach to disability and social welfare, arguing that this could reduce competition for resources and influence.

"Inside the municipality for example, could you think about combining the services that go under the social welfare and disability acts under the same organisation, so that you don't start competing for the funding?" (Finland, local official in health services)

Many suggestions focused on how to improve participation at the local level, where deinstitutionalisation takes place in practice. They pointed to existing cooperation structures and networks as models to replicate elsewhere.

"The focus on social innovation in recent years, including as concerns disability, aims to try to develop independent living paths that are connected to the local network. From our point of view, this is essential to develop real and tangible independent living paths." (Italy, employee of community-based service)

In this respect, participants highlighted the crucial role of regional and local level politicians in ensuring the involvement of different sectors. Service providers called for greater involvement of frontline practitioners, highlighting that they possess the practical knowledge and experience that politicians and policymakers may lack. Others stressed the benefit of less formal ways of working between all sectors.

Participants also highlighted the mutually reinforcing nature of horizontal and vertical cooperation, and proposed a number of concrete measures to achieve this, including:

- adopting a deinstitutionalisation strategy with a strong focus on cooperation;
- creating a sustainable platform for communication between and among different actors;
- appointing a focal point under the ministry responsible for deinstitutionalisation;
- creating a multi-level and multi-sectoral taskforce to coordinate activities and enable mutual learning, and exchange of experiences and knowledge.

Involvement of persons with disabilities, their families and representative organisations is a clear gap in policymaking processes at all levels. Participants highlighted the importance of persons with disabilities having the opportunity to contribute to decision-making processes.

"I think [people with disabilities] should have opportunities to talk about this issue themselves, not only us officials or lobbying organisations, I think people with disabilities should be there, telling 'This is what I think'. Because they have the experience. So whether decisions are made on a national level, or on a regional level, or on a municipal level, it would be nice if people with disabilities could participate in that, so they could say, 'Have you thought about the implications of this decision?'." (Finland, local policymaker)

4.4. Availability of guidance to support the deinstitutionalisation process

"States should ensure that personnel working or about to work in disability-related services [...] are adequately trained on independent living within the community, in theory and practice."
"State parties should provide and disseminate timely, up-to-date and accurate information essential for informed decision-making on choices of independent living and support services in the community."
CRPD Committee (2017), *General comment No. 5 (2017) on living independently and being included in the community*, CRPD/C/GC/5, 27 October 2017, paras. 65 and 64.

---

[93] CRPD Committee (2017), *General comment No. 5 (2017) on living independently and being included in the community*, CRPD/C/GC/5, 27 October 2017, para. 97 (i).

[94] FRA (2017), *From institutions to community living- Part I: commitments and structures*, Luxembourg, Publications Office; FRA (2017), *From institutions to community living-Part II: funding and budgeting*, Luxembourg, Publications Office.

The General Comment on Article 19 addresses various forms of guidance. It highlights the role of "legislative guidelines" in clarifying how to implement legal requirements, and calls on States parties to provide training for relevant stakeholders and information for persons with disabilities. In addition to these points, participants in the research called for greater efforts to make use of existing good practices and prepare persons with disabilities and their families for the deinstitutionalisation process.

The preparation and dissemination of practical tools and guidelines emerged from the research as crucial in fostering successful deinstitutionalisation. They urged the development of additional and, crucially, practical guidance on how to translate CRPD principles and legislation into actionable steps in their daily work. Participants, especially those at the local level, assigned this responsibility primarily to national authorities, but underlined the necessity that it be prepared on the basis of cooperation and consultation with those with practical experience. Given the complexity of the process, some participants proposed creating expert teams to provide advice and guidance.

Participants strongly advocated more – and better targeted – training opportunities for staff participating in the transition process, whether newly recruited or long-serving. They identified it as a key way to overcome institutional practices and embed the principles of choice and control in the delivery of disability services. Several core components of this training recurred across the measures proposed by participants in the five countries. Firstly, training should be based on the human rights-based model of disability and grounded in the rights set out in the CRPD. Secondly, it should be practical rather than theoretical, and incorporate the sharing of practices from other regions or countries.

> *"Training should also be lived in the field, also seeing other experiences. That is, choosing the most significant experiences that are implemented in other places, thereby enabling people to spend time in other contexts. Because this widens perspectives and opportunities, and makes people understand that there are different ways [of doing things]."* (Italy, local policymaker)

Thirdly, frontline staff and their managers emphasised that training should be on-going and promote reflection on what is working well and less well in trying to deliver on the promise of deinstitutionalisation. Finally, some called for a fundamental rethink of how social work is taught at university and other training centres, arguing that this would ensure a new generation of employees trained in independent living principles and practice.

Many participants suggested a need for additional efforts to prepare persons with disabilities and their families for deinstitutionalisation. Providing adequate, relevant and timely information is central to this preparation, they felt. Where formal measures are in place for such preparation, participants felt that they made a significant contribution to successful deinstitutionalisation, and strongly advocated their use. In situations where preparation is more informal, many participants agreed that taking time and ensuring a person-centred approach to providing this information is crucial. Opinions differed, however, as to whether this was better done before or after an initial transition. Some participants went further and cautioned against excessive preparation, which they felt could delay deinstitutionalisation.

Drawing on good practices and pilot projects across localities, regions and countries helps to equip actors in the deinstitutionalisation process with concrete examples to apply in their own work, participants emphasised. Recalling their own positive experiences of learning exchanges, they called for more such opportunities to be available.

> *"Sharing of information [...] is a must. Relevant experience, whether positive or negative, can only be shared if there is actively created social network of institutions, municipalities and towns, clients and family members. It is necessary to learn from mistakes of others and follow examples of good practice."* (Slovakia, employee of a community-based service)

4.5. Practical organisation of the deinstitutionalisation process

"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."

UN 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

Guidance on how best to organise deinstitutionalisation in practice runs throughout the General Comment on Article 19. It includes many of the steps advocated by participants in this research, ranging from "individualized plans for transition with budgets and time frames" to ensuring "accessible employment".[95] Underpinning all of these elements is the development of community-based services responsive to the needs of persons with disabilities. This, the CRPD Committee insists, requires a systematic approach incorporating both

---

[95] CRPD Committee (2017), *General comment No. 5 (2017) on living independently and being included in the community*, CRPD/C/GC/5, 27 October 2017, paras. 58 and 33.

disability-specific support services and general services open to the public.

Participants were unanimous that without the presence of a range of specialised support services for persons with disabilities in the community, the deinstitutionalisation process is doomed to fail. They strongly argued for the development of new and innovative services to fill the current gap. In addition to this general call, they also made concrete suggestions about the specific nature of the services required. Their proposals reflect the CRPD Committee's insistence that "persons with disabilities have the right to choose services and service providers according to their individual requirements and personal preferences".[96]

Many participants across countries and stakeholder groups reiterated the importance of a person-centred approach to service provision. They drew on their own experiences to suggest ways to achieve this goal:

- Building services around individuals: participants called for service design to focus on how to achieve better outcomes for each individual, rather than on how to meet the requirements of rules and regulations. This, they argued, requires building up strong relationships with service users.

"It's really about getting to know the individual, respecting their needs and looking at their history." (Ireland, national official)

- Replacing services catering to group needs with individualised services: participants noted the key role of adequate staff support in ensuring that service users can undertake activities independently. Staff resources can be maximised by incorporating activities supervised by external facilitators into a service user's day, adding extra staff hours for certain times of the week and enlisting volunteers, participants suggested.
- Separating housing from support: the services a person with disabilities can access often depend on the type of accommodation they live in. Many participants felt that this perpetuates institutional approaches in the community. They advocated decoupling the two as a way to strengthen the choice and control people with disabilities have over the services they receive.

"Prevention of the institutional culture is an important factor, it should be achieved by clear and unconditional division between the place people live and the place they receive support. Otherwise, by merging them we create an institution in every sense of the word." (Bulgaria, employee of a community-based service)

- Ensuring that the 'money follows the person': participants recommended that funding be assigned according to individual needs. To facilitate this, some advocated for the introduction of personal budgets and direct payment schemes (see Section 4.1.).
- Finding a balance between ensuring an adequate level of support and not over-supporting persons with disabilities.

"It is not like a walking aid that is always there, instead we take the crutches away as soon as they can walk even a bit, we have to look at the support needs carefully so that they do not become dependent, but the support is there for them to understand what they have to do, and then do it by themselves." (Finland, employee of employment services)

- Supporting innovative services: some participants suggested simplifying rules and regulations to enable innovation. Others called for greater involvement of other actors, such as NGOs and the broader third sector.

"[What will drive the process forward is] [a]llowing clear experimentations instead of bureaucratic ones, simplifying and financing actions such as apartment groups and semi-autonomous cohabitations." (Italy, employee of a community-based service)

"I really believe there should be an entire spectrum [of providers]. And [I would be inclined towards] non-public providers. […] They are able to provide [various services] and lend these services a different dimension. After all, we want the clients to be free in terms of choosing where they will go." (Slovakia, regional policymaker)

Turning to the availability and accessibility of general services, participants across stakeholder groups called for measures to combat the physical and attitudinal barriers people with disabilities face. Without them, people with disabilities will continue to have no option but to use segregated housing, health or transport services. Reflecting the fact that most participants' work focuses on disability services, they had fewer concrete suggestions on how to make general services more accessible. Nevertheless, participants urged additional steps to make social housing accessible as a way to increase the range of housing options for persons with disabilities, and called for more employment opportunities for persons with disabilities.

Finally, participants highlighted the importance of building up service users' independence by developing their independent living skills. This is needed before, during and after the deinstitutionalisation process, they emphasised. Some participants advocated greater use of 'training homes' for persons with disabilities moving from institutions or the family home to accommodation in the community, as a way to acclimatise to independent living prior to the transition.

---

[96] CRPD Committee (2017), *General comment No. 5 (2017) on living independently and being included in the community*, CRPD/C/GC/5, 27 October 2017, para. 28.

Annex 1: Overview of drivers of and barriers to deinstitutionalisation

Table 9 presents an overview of the key drivers of and barriers to deinstitutionalisation emerging from FRA's research.

Table 9: Overview of drivers of and barriers to deinstitutionalisation

Key drivers	Essential feature of deinstitutionalisation	Key barriers
National political commitment to deinstitutionalisation Political commitment at the national level, backed up with adequate policies and implementation measures, is crucial for successful deinstitutionalisation.	Commitment to deinstitutionalisation	**Insufficient, difficult to access or poorly assigned funding** Insufficient, poorly spent or difficult to access funding is a recurring barrier. Some participants, however, pointed to examples of good results achieved in the absence of specific funding.
Commitment at local level For the process to move forward, national commitment should be complemented by commitment at the local level. Local-level commitment can serve to inform, strengthen and campaign for greater national commitment.		**Vested interests trying to block deinstitutionalisation** Participants spoke of instances of corruption, and reluctance on the part of providers of institutional services to change existing models.
External pressure to hasten deinstitutionalisation National commitment sometimes emerges in response to external pressures from the media, monitoring reports and the EU itself, particularly in relation to ESIF. However, many participants questioned if this would produce reactive results that could be of poorer quality.		**Deprivation of legal capacity** Deprivation of legal capacity can lead to or lengthen institutionalisation and contributes to risk aversion among staff, resulting in people being assessed as needing much higher levels of support than they actually do.
Persons with disabilities demanding deinstitutionalisation Empowerment of persons with disabilities is a crucial aspect of commitment to deinstitutionalisation.		
Changes in public attitudes towards persons with disabilities Deinstitutionalisation creates a 'virtuous cycle': as people with disabilities become more visible in the community, communities are more welcoming of them, making the transition process easier.	A change in attitudes towards persons with disabilities	**Institutional models of 'care' persisting** Strongly embedded beliefs that people with disabilities should be 'looked after' and 'cared for' both prevent people from leaving institutions and lead to the persistence of institutional practices in community-based services.
Media and individual stories redefining public perceptions of people with disabilities Positive representations of people with disabilities can help to reshape perceptions of disability and counter 'fear of the unknown'.		**Learned dependence of persons with disabilities** Institutionalisation often leaves people with disabilities without the basic independent living skills needed in the community.
Changes in staff attitudes towards people with disabilities Staff committed to independent living empower people with disabilities to transition to the community and set a positive example for other colleagues.		**Family resistance to deinstitutionalisation** Families are often reluctant to support deinstitutionalisation for their relatives because of concerns about the availability of community-based services and about safety and security in the community.

Cooperation at local level Effective cooperation between different actors at the local level is an essential component of successful deinstitutionalisation. This can take the form of formal working groups or networks, or more informal working relationships between different actors.	**Active cooperation between the people involved in the deinstitutionalisation process**	**Lack of cooperation between and across sectors** Inadequate or ineffective cooperation can create confusion about responsibilities for implementing deinstitutionalisation. Participants reported a tendency to focus only on their role rather than on the process as a whole.
Cooperation with the families of persons with disabilities Involving families throughout the deinstitutionalisation process helps to overcome any resistance to the transition, and allows families to participate actively in the process.		**Lack of cooperation between different levels of governance** Gaps in cooperation between national, regional and local actors can leave practitioners feeling excluded from decision-making processes around deinstitutionalisation. It also increases the risk of developing policies that prove unworkable in practice.
Cooperation with actors bringing innovation and change Cooperating with third sector organisations and NGOs brings innovative ideas and experiences to the deinstitutionalisation process.		**Lack of cooperation with the local community** Not involving the local community in deinstitutionalisation processes can further entrench resistance to deinstitutionalisation.
Pilot projects showcasing how deinstitutionalisation works in practice Visiting pilot projects and learning exchanges allows stakeholders to acquire new knowledge and ideas on how to implement deinstitutionalisation.	**Availability of guidance to support the deinstitutionalisation process**	**Insufficient guidance from national to local level** Lack of actionable guidance from national policymakers makes it more difficult for practitioners to implement deinstitutionalisation law and policy in practice.
Staff (re-)training and recruitment Recruiting new staff and re-training existing ones is an essential component of instilling an independent living philosophy in disability services.		**Insufficient preparation and information for persons with disabilities and their families** Lack of information about how and when deinstitutionalisation will take place can create confusion and reduce the ability of persons with disabilities and their families to participate actively in the process.
Individual support plans for persons with disabilities Individual plans can help to identify an individual's wishes and support persons with disabilities during and after deinstitutionalisation.	**Practical organisation of the deinstitutionalisation process**	**Lack of specialised support services in the community for people with disabilities** The absence of appropriate community-based services for persons with disabilities prevents people from leaving institutions and impedes the full realisation of independent living in the community.
Developing independent living skills Opportunities to develop everyday skills, for example in so-called 'training apartments', help to equip people with disabilities for life in the community.		**Inaccessible general services, including housing, health and transport services** Many services available to the general public are inaccessible for persons with disabilities, leaving them without crucial support and unable to participate in community life on an equal basis with others.
		Inflexible rules and regulations on the provision of services to people with disabilities Excessively rigid rules and regulations can perpetuate an institutional culture in community-based services and suppress innovation.
		Lack of employment opportunities People with disabilities face numerous barriers to entering the labour market, depriving them of a crucial route to financial stability and social inclusion.
		Staff working conditions Concern among staff that their working conditions will deteriorate as a result of deinstitutionalisation can undermine their support for the process.

Source: FRA, 2018

Annex 2: Methods and design

Between 2014 and 2018, FRA implemented a multiannual project to collect and analyse comparable data on the right to independent living of persons with disabilities in the EU. The overall objective of this project is to provide evidence-based assistance and expertise to EU institutions and Member States on how to fulfil the right of persons with disabilities to live independently and be included in the community, as set out in Article 19 of the CRPD. The project specifically focuses on the process of deinstitutionalisation.

The complexity of the issue and the lack of previous research in the area required dividing the project into three phases. Each phase used a different methodology:

- **Phase 1 – Taking stock**: mapping what types of institutional and community-based services for persons with disabilities are available in the 28 EU Member States. A summary overview of this mapping, along with background country data for each Member State, was published in 2017.[97]
- **Phase 2 – Identifying implementation gaps**: developing and applying human rights indicators to help assess progress in fulfilling Article 19 of the CRPD and support ongoing efforts to implement the right to independent living. Three reports addressing key issues emerging from the indicators were published in 2017.[98] The reports are also available in easy read.[99]
- **Phase 3 – Fieldwork**: conducting qualitative research in five EU Member States at different stages of the deinstitutionalisation process to identify and better understand the drivers of and barriers to the transition from institutional to community-based support.

FRA's in-country research network, FRANET,[100] collected the data for all three phases of the research, on the basis of detailed instructions provided by FRA. The first two phases consisted of desk research covering all 28 EU Member States. FRA then identified the Member States where the primary fieldwork research on deinstitutionalisation took place (Phase 3), drawing on findings from the first two phases. This annex focuses on the methodology used in Phase 3. More information on the methodologies used for phases 1 and 2 is available on the FRA website.[101]

Selecting the Member States for the fieldwork

FRA conducted extensive background research to identify the five EU Member States where the research took place. This included:

- Analysis of the information gathered in Phase 2 of the project.
- Discussions on the selection of countries with a range of stakeholders, including: policymakers at EU and national level, researchers and experts on disability issues, and DPOs;
- Liaising with the European Expert Group on the transition from institutional to community-based care, as well as with the CRPD Working Group of the European Network of National Human Rights Institutions.

Drawing on this information, FRA completed a matrix to help determine in which Member States to conduct the fieldwork. This matrix divided Member States into groups according to two main criteria:

- progress towards community-based support: whether the deinstitutionalisation process is just beginning in the Member State, whether it is already underway, or whether it has already been fully or partially implemented;
- whether a policy commitment to deinstitutionalisation is in place: whether or not there is an action plan/strategy on deinstitutionalisation.

The following criteria, in order of importance, also supported the selection of Member States:

- geographical balance to ensure the widest possible relevance;
- different types of social welfare systems (state-provided services or services based on user contributions; services commissioned, funded and provided at the national or local level) to capture how the way services are provided affects deinstitutionalisation;
- socio-economic context to reflect different resources available to support the deinstitutionalisation process;
- federal and unitary states to reflect different centres of decision-making concerning deinstitutionalisation;
- language competence of FRA staff to facilitate close monitoring of the fieldwork.

---

[97] FRA (2017), *Summary overview of types and characteristics of institutional and community-based services for persons with disabilities available across the EU*, Luxembourg, Publications Office.

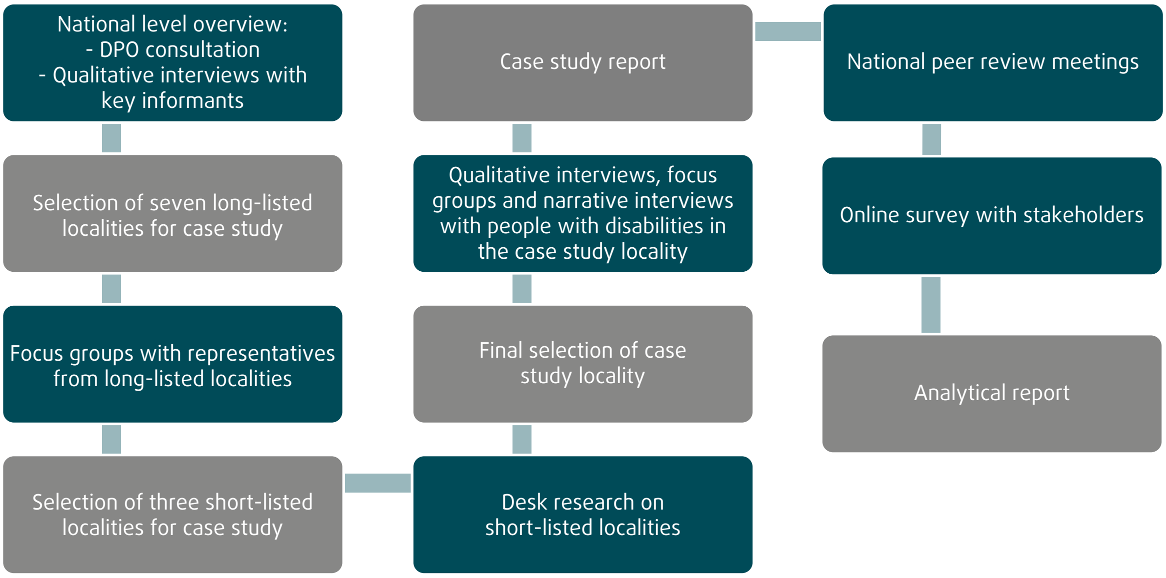
[98] FRA (2017), *From institutions to community living – Part 1: commitments and structures*, Luxembourg, Publications Office; FRA (2017), *From institutions to community living – Part 2: funding and budgeting*, Luxembourg, Publications Office; FRA (2017), *From institutions to community living – Part 3: outcomes for persons with disabilities*, Luxembourg, Publications Office.

[99] All FRA's easy read publications are available online.

[100] See FRA's webpage on FRANET.

[101] See the main project webpage on FRA's website.

Figure 3: Main activities of the fieldwork research



Source: FRA, 2018

Following this process, five countries were selected for the fieldwork: Bulgaria, Finland, Ireland, Italy and Slovakia.

The stages of the fieldwork research

The fieldwork consisted of in-depth research in the five Member States to understand the drivers of and barriers to the transition from institutional to community-based support. It was divided into four parts:

1. Identifying key themes and understanding the national and local context.
2. In-depth case study in one locality.
3. Validating the findings of the fieldwork.
4. Comparative analysis of drivers and barriers.

Figure 3 illustrates the main activities of the fieldwork, with each stage building on the previous one. The first part established a baseline for the status of deinstitutionalisation at the national level, which informed the exploration of how the transition process is implemented at the local level. These findings guided the design of the case study in part two. The evidence from parts one and two were then shared with representatives of the different groups of stakeholders involved in deinstitutionalisation to ascertain that they correspond with their experiences. This verification process enabled FRA to draw comparative conclusions about the drivers of and barriers to deinstitutionalisation. Segmenting the research in this way ensured that its conclusions are relevant beyond the confines of the specific localities and Member States.

The research included participants from the key groups of stakeholders involved in making independent living a reality for persons with disabilities:

- national level policymakers and experts,
- local level policymakers,
- managers and employees of institutional and community-based services,
- employees of other services, such as health, employment or housing,
- persons with disabilities,
- family members of persons with disabilities,
- national and local DPOs, and
- members of local communities.

Throughout the research, participants were asked about their understanding of central concepts related to deinstitutionalisation and to identify drivers of and barriers to the process. Particular attention was paid to measures participants think need to be implemented to ensure successful deinstitutionalisation.

The fieldwork began with a consultation with DPOs; semi-structured interviews with selected national stakeholders; semi-structured focus group discussions with local stakeholders; and desk research to identify possible localities that could serve as case studies. For the purpose of this research, 'locality' means a local level administrative region or unit.

The consultation with DPOs explored how the full participation of persons with disabilities could be ensured in the fieldwork (see box). It involved 21 DPOs across the five countries, selected on the basis of their experience in conducting and/or participating in qualitative research on the rights of persons with disabilities, where possible on deinstitutionalisation. The consultation also enabled the FRANET contractors to learn practical techniques to ensure that persons with disabilities could meaningfully participate in the research on an equal basis with others.

The semi-structured interviews with national-level stakeholders served to gather contextual information about the situation of the transition from institutional to community-based support at the national level. These interviews also helped to identify key themes to explore in greater detail during the subsequent focus groups and case studies. Twenty-seven interviews were held across the five Members States, with participants selected from the following stakeholder groups:

- national coordinators on deinstitutionalisation at relevant ministries,
- national officials responsible for community-based services for persons with disabilities,
- national officials responsible for institutions for persons with disabilities,
- national officials responsible for managing European Structural and Investment Funds (ESIF), where these officials are involved in managing funds relevant to the transition from institutional to community-based care and support,
- representatives of Article 33(2) CRPD monitoring mechanisms, and
- representatives of national independent living movements.

The FRANET contractors then conducted desk research to identify a long-list of seven localities in each Member State where the case study could take place. In addition to the findings of the consultation with DPOs and the semi-structured interviews, the following criteria were used to select these localities:

- existence of an institution(s) for persons with disabilities in the locality,
- local political commitment to deinstitutionalisation,
- DPO/civil society organisations working on the rights of persons with disabilities active in the locality,
- previous, on-going or planned deinstitutionalisation process,
- use of ESIF for deinstitutionalisation processes,
- additional information: types of community-based services in the locality; population size, density and

Ensuring the participation and involvement of persons with disabilities in the fieldwork

FRA took careful steps to actively include persons with disabilities and their representative organisations throughout the fieldwork, from the initial planning through to implementation and review.

During the planning process, FRA conducted stakeholder consultations to inform the development of the fieldwork research, including with persons with disabilities and their representative organisations. As part of these consultations, FRA hosted an expert meeting to discuss appropriate methodologies to use in the fieldwork. This meeting brought together disabled persons organisations (DPOs); civil society organisations working in the area of disability; academic experts in the fields of research methods and disability studies, and a representative from a national CRPD monitoring framework. Participants at the meeting discussed methodological issues relevant to the successful implementation of the fieldwork. These discussions assisted FRA in identifying the most appropriate methods and in developing suitable tools to ensure the meaningful participation of persons with disabilities in the research, irrespective of types and degrees of impairments.

FRA further conducted dedicated consultations with DPOs active in each of the five Member States. These consultations centred on how to ensure the full participation of persons with disabilities in the fieldwork, including identifying the most appropriate strategies for recruiting participants, choosing accessible research methods and developing accessible research tools.

A number of steps were taken to ensure accessibility during the implementation phase. This included ensuring that any premises where interviews and focus groups took place were fully accessible; enabling participants to take breaks when needed; providing an appropriate space for personal assistants to wait; and holding interviews and focus groups at times that allowed participants to travel with public transport. Additional reasonable accommodations were made based on specific needs.

In addition, FRA developed easy read versions of the research tools used to conduct the interviews and focus groups, the information sheets on the project, and the consent forms. The narrative interview methodology was specifically chosen on the basis of its suitability for persons with intellectual disabilities.

During the review part, persons with disabilities and their representative organisations took part in national peer review meetings, as well as in an online survey implemented by FRA to validate the local-level findings. Every effort was made to make the peer review meetings and online survey accessible.

characteristics; rural/urban location; socio-economic situation.

Three sets of homogenous, semi-structured focus groups were held with stakeholders from across the seven localities in each of the Member States. The first set brought together representatives of local public authorities; the second set, representatives of institutions and community-based services; and the third set, persons with disabilities living in institutions and/or involved in transition processes and/or using community-based services. In total, 171 persons participated in these focus groups, which aimed to identify commonalities and differences in experiences and perceptions of drivers and barriers of deinstitutionalisation. By bringing together participants from different localities, the focus groups enabled FRA to identify key issues, themes and processes to examine during the case study.

The findings of the focus groups informed the selection of a short-list of three localities in each of the Member States. This selection also drew on findings from the national-level interviews. The short-list further reflected the following criteria:

- willingness of local authorities to participate in the research;
- availability of staff and service users to be interviewed as part of the research;
- risks to sustainability of support, for example, upcoming local elections that could result in a change of administration or policies related to deinstitutionalisation.

The FRANET contractors then conducted detailed desk research on the three short-listed localities in each Member State. This informed FRA's selection of the case study locality in each country.

The case study consisted of semi-structured interviews with participants involved in the transition from institutional to community-based support; narrative interviews with persons with disabilities; and focus groups with local-level actors. All interviews and focus groups took place in the case study locality.

The 50 participants in the semi-structured interviews in the case study locality in each of the five Member States came from the following participant groups:

- Local officials/policymakers responsible for: the transition from institutional to community-based support; community-based services; institutional services; and health services.
- Senior managers of: institutional services; community-based services; services providing personal assistance.
- Employees of: institutional services; community-based services.
- Employees of general services with experience of working with persons with disabilities, including: health services; employment services; housing services.
- Representatives of DPOs working on deinstitutionalisation/independent living.

Unstructured, in-depth, individual narrative interviews were held with persons with disabilities so that they could give a personal account of how they experience(d) deinstitutionalisation. In total, 21 narrative interviews were conducted across the five Member States. These interviews consisted of two conversations, with the first allowing participants to tell the story of their experience with deinstitutionalisation. The second conversation served to confirm and explore this story in more depth. Prior to the second conversation, the interviewer prepared a story based on the first conversation, which was shared with the participant. The second conversation allowed participants to comment on whether this story accurately reflected their experiences or if they would like to remove, add or change elements so that the story would be true to their experience.

The homogenous, semi-structured focus groups with local-level actors aimed to collect the views and experiences of different actors in the transition process in each locality. In total, 100 persons participated in these focus groups across the five Member States. These focus groups helped to further elaborate on the drivers of and barriers to deinstitutionalisation identified in previous stages of the research, and to explore the different perspectives of the wide range of actors involved in the deinstitutionalisation process in each locality. Three categories of participants participated:

- Family members of persons with disabilities living in institutions, and family members and/or carers of persons with disabilities using community-based services (32 participants).
- Employees of institutional or community-based services from a range of different services (35 participants).
- People who live, work or provide services in the local community, preferably living in the proximity of institutions and/or community-based services (33 participants).

Following the completion of the interviews and focus groups, the FRANET contractors prepared a national case study report for each Member State. These reports captured the results of the interviews and focus groups with national and local stakeholders, conducted under part one, as well as the interviews and focus groups comprising the in-depth case study, conducted under part two.

Validating the findings of the fieldwork

FRA hosted one peer review meeting in each of the five Member States to help validate the findings of the fieldwork. Held in the national language, these meetings were attended primarily by research participants, as well as a small number of other stakeholders. These included national and local policy makers, service providers, national human rights bodies, civil society organisations, representatives of academia, persons with disabilities and DPOs. In total, 109 persons participated in these meetings across the five Member States.

The peer review meetings allowed participants to reflect and provide feedback on the national findings, as presented in the respective national case study. These reports were shared with the participants in advance of the meetings. The feedback from participants on the research was overwhelmingly positive in all five countries. Participants indicated that the research accurately captured the different perspectives of the wide range of actors involved in deinstitutionalisation, giving a comprehensive overview of drivers and barriers of the process at the national level.

Discussions held at these peer review meetings fed into the revision of the national case study reports and informed the drafting of this analytical report. These meetings also provided an opportunity to discuss how, and to whom, the research findings could be communicated to maximise the impact of the project at the national level.

FRA also implemented an online survey to complement the fieldwork and provide further validation of the research findings. Most respondents had participated in the different stages of the fieldwork. In addition, selected local, regional and national stakeholders were invited to participate. The survey was conducted in the five national languages.

The online survey took place over two rounds, between 29 August and 20 November 2017. In total, 249 participants from across the five Member States and the seven stakeholder groups included in the research participated in the first round. They were asked to:

1. rank the five key features of deinstitutionalisation that emerged from the analysis of the fieldwork materials; and

2. rate the importance of the drivers and barriers identified under each of these features, as well as provide an open-ended justification for this rating.

The ranking of the five features revealed what the stakeholders involved in deinstitutionalisation think are the most important aspects of the process as a whole. The rating enabled a more detailed analysis of specific drivers of and barriers to deinstitutionalisation, grouped under each of the five features. This analysis was conducted in the second round of the online survey.

All those who participated in the first round of the survey were invited to take part in the second round, with 150 participating. In this round, participants were asked to rank the importance of 10 drivers and 10 barriers that emerged from the rating that had been done in the first round. The list of drivers to be ranked included the two drivers that received the highest rating under each of the key features. The same procedure was followed for the list of barriers. This approach allowed the results to be analysed by country and respondent group. More information on the methodology implemented for the online survey and its findings can be found on FRA's website.[102]

---

[102] For more information on FRA's Delphi process, see the background document available on FRA's website.

Getting in touch with the EU

In person

All over the European Union there are hundreds of Europe Direct information centres. You can find the address of the centre nearest you at: https://europa.eu/european-union/contact_en

On the phone or by email

Europe Direct is a service that answers your questions about the European Union.
You can contact this service:
– by freephone: 00 800 6 7 8 9 10 11 (certain operators may charge for these calls),
– at the following standard number: +32 22999696 or
– by email via: https://europa.eu/european-union/contact_en

Finding information about the EU

Online

Information about the European Union in all the official languages of the EU is available on the Europa website at: https://europa.eu/european-union/index_en

EU publications

You can download or order free and priced EU publications at: https://publications.europa.eu/en/publications. Multiple copies of free publications may be obtained by contacting Europe Direct or your local information centre (see https://europa.eu/european-union/contact_en).

EU law and related documents

For access to legal information from the EU, including all EU law since 1952 in all the official language versions, go to EUR-Lex at: http://eur-lex.europa.eu

Open data from the EU

The EU Open Data Portal (http://data.europa.eu/euodp/en) provides access to datasets from the EU. Data can be downloaded and reused for free, both for commercial and non-commercial purposes.

FRA
EUROPEAN UNION AGENCY
FOR FUNDAMENTAL RIGHTS

HELPING TO MAKE FUNDAMENTAL RIGHTS A REALITY FOR EVERYONE IN THE EUROPEAN UNION

The Convention on the Rights of Persons with Disabilities commits both the EU and all of its Member States to realising the right of persons with disabilities to live independently in the community – which includes achieving deinstitutionalisation for those residing in institutional settings. But much remains to be done to make this a reality in practice.

This report presents the main insights gained during fieldwork on the drivers of and barriers to deinstitutionalisation. Focusing on the local level, it gives voice to a diverse set of actors – most importantly, to people with disabilities themselves. It also outlines input from the families of individuals going through the transition to community-based living, members of local communities, and the various people responsible for designing the process and implementing it on a daily basis.

In so doing, it can serve as an important resource for policymakers looking to take this important work forward – with the ultimate goal of ensuring that people with disabilities can live independently in the community on an equal basis with others.

Equality

People with disabilities

FRA - EUROPEAN UNION AGENCY FOR FUNDAMENTAL RIGHTS
Schwarzenbergplatz 11 – 1040 Vienna – Austria
Tel. +43 1580 30-0 – Fax +43 1580 30-699
fra.europa.eu – info@fra.europa.eu
facebook.com/fundamentalrights
linkedin.com/company/eu-fundamental-rights-agency
twitter.com/EURightsAgency

Publications Office