

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

Summary



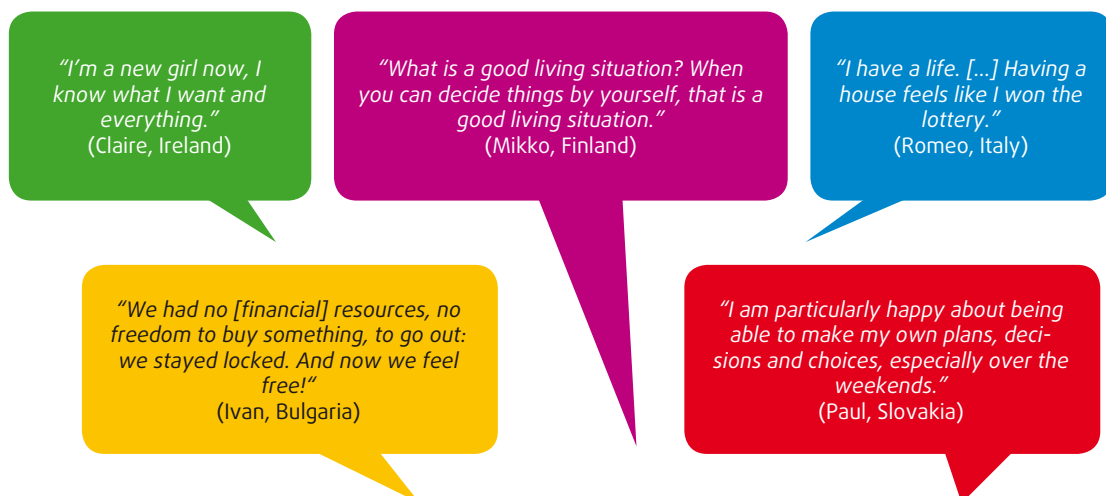
The Charter of Fundamental Rights of the European Union sets out rights that are particularly relevant to persons with disabilities. The most important are the integration of persons with disabilities (Article 26) and non-discrimination (Article 21).

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. Making the transition from institutional to community-based forms of living and support arrangements is also called deinstitutionalisation. It is, however, proving a considerable

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



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

challenge for EU Member States.¹ Concerns over cost, the impact on staff currently working 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.

The European Union Agency for Fundamental Rights (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. The *Annex* gives an overview of the key drivers and barriers emerging from the research.

This summary report presents the key findings of that fieldwork and the FRA opinions stemming from them. The main report, *From institutions to community living for persons with disabilities: perspectives from the ground*, presents the detailed findings of the fieldwork. In addition, the five national case studies that accompany the main report present the results of the fieldwork in each country.²

What is deinstitutionalisation?

Article 19 of the United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD) sets out the right of people with disabilities 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 lies at the heart of the convention and is the core global standard for

independent living. 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.

Article 19 of the CRPD sets out a positive vision of “living in the community, with choices equal to others”. It 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)).³

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”.⁴ 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

1 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.

2 <https://fra.europa.eu/en/country-data/2018/right-independent-living-case-studies>.

3 These three components are analysed in greater depth by the 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.

4 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.

these should be replaced with “independent living support services”.⁵

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.”⁶ 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.⁷ This summary report uses ‘the transition from institutional to community-based support’ interchangeably with ‘deinstitutionalisation’.

⁵ 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.

⁶ 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.

⁷ 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.

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.⁸ 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 the Annex). 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 participants in the

Table 1: Key features of a successful deinstitutionalisation process

Key feature	Explanation
Commitment to deinstitutionalisation	<ul style="list-style-type: none"> 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	<ul style="list-style-type: none"> 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	<ul style="list-style-type: none"> 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	<ul style="list-style-type: none"> 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	<ul style="list-style-type: none"> 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

⁸ 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.



research also proposed a wealth of other practical suggestions. 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.⁹

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 training 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.

⁹ 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.¹⁰

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.

¹⁰ FRA (2013), *Legal capacity of persons with intellectual disabilities and persons with mental health problems*, Luxembourg, Publications Office.

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. 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 work. 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 daycare 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, deepen 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.

Annex: Overview of drivers of and barriers to deinstitutionalisation

Table 2 presents an overview of the key drivers of and barriers to deinstitutionalisation emerging from the FRA research.

Table 2: Overview of drivers of and barriers to deinstitutionalisation

Key drivers	Essential feature of deinstitutionalisation	Key barriers
<p>National political commitment to deinstitutionalisation Political commitment at the national level, backed up with adequate policies and implementation measures, is crucial for successful deinstitutionalisation.</p>	<p>Commitment to deinstitutionalisation</p>	<p>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.</p>
<p>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.</p>		<p>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.</p>
<p>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.</p>		<p>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.</p>
<p>Persons with disabilities demanding deinstitutionalisation Empowerment of persons with disabilities is a crucial aspect of commitment to deinstitutionalisation.</p>		<p>A change in attitudes towards persons with disabilities</p>
<p>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’.</p>	<p>Learned dependence of persons with disabilities Institutionalisation often leaves people with disabilities without the basic independent living skills needed in the community.</p>	
<p>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.</p>	<p>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.</p>	



<p>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.</p>	<p style="writing-mode: vertical-rl; transform: rotate(180deg);">Active cooperation between the people involved in the deinstitutionalisation process</p>	<p>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.</p>
<p>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.</p>		<p>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.</p>
<p>Cooperation with actors bringing innovation and change Cooperating with third sector organisations and NGOs brings innovative ideas and experiences to the deinstitutionalisation process.</p>		<p>Lack of cooperation with the local community Not involving the local community in deinstitutionalisation processes can further entrench resistance to deinstitutionalisation.</p>
<p>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.</p>	<p style="writing-mode: vertical-rl; transform: rotate(180deg);">Availability of guidance to support the deinstitutionalisation process</p>	<p>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.</p>
<p>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.</p>		<p>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.</p>
<p>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.</p>	<p style="writing-mode: vertical-rl; transform: rotate(180deg);">Practical organisation of the deinstitutionalisation process</p>	<p>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.</p>
<p>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.</p>		<p>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.</p>
		<p>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.</p>
		<p>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.</p>
		<p>Staff working conditions Concern among staff that their working conditions will deteriorate as a result of deinstitutionalisation can undermine their support for the process.</p>

Source: FRA, 2018

Further information:

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

For the full FRA report *From institutions to community living for persons with disabilities: perspectives from the ground*, see: <http://fra.europa.eu/en/publication/2018/independent-living-reality>.

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 that 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 that 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 Bulgarian, English, Finnish, Italian and Slovakian.

In addition, FRA has published:

- human rights indicators on Article 19 of the CRPD, including a number of statistical outcome indicators;
- a summary overview of types and characteristics of institutional and community-based services for persons with disabilities in the 28 EU Member States.

For an overview of FRA activities on the rights of persons with disabilities, see: <http://fra.europa.eu/en/theme/people-disabilities>.



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Schwarzenbergplatz 11 – 1040 Vienna – Austria
Tel: +43 158030-0 – Fax: +43 158030-699
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