

From institutions to community living: key findings and FRA opinions

Summary



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

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

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

Article 19 of the United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD) sets out the right to live independently and be included in the community. It lies at the heart of the convention. It represents “the sum of the various parts of the convention” and brings together the principles of equality, autonomy and inclusion.¹ These underpin the convention’s human rights-based approach to disability. This paper shortens the name of the right to the right to independent living. All but one of the EU Member States, and the EU itself, have ratified the CRPD, committing themselves to achieving independent living for persons with disabilities.

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

The CRPD does not specifically mention deinstitutionalisation. However, the Committee on the Rights of Persons with Disabilities (CRPD Committee) has underlined that it is an essential component of fulfilling Article 19, given that “independent living and being included in the community refer to life settings outside residential institutions of all kinds”.²

There is no internationally accepted definition of deinstitutionalisation. The UN Office of the High Commissioner for Human Rights (OHCHR) has described it as “a process that provides for a shift in living arrangements for persons with disabilities, from institutional and other segregating settings to a system enabling social participation where services are provided in the community according to individual will and preference”.³ This report uses ‘the transition from institutional to community-based support’ interchangeably with ‘deinstitutionalisation’.

Achieving this transition is therefore not limited to changing the place or type of residence. Instead, it entails a profound shift from environments characterised by routine and an ‘institutional culture’ to those where persons with disabilities exercise choice and control over their lives and any support they may require. As such, ‘deinstitutionalisation’

² See, in particular, CRPD Committee (2017), *General Comment No. 5 – Article 19: Living independently and being included in the community*, CRPD/C/18/1, 29 August 2017, para. 16 (c). Many organisations, including FRA, submitted written comments on the draft General Comment.

³ United Nations General Assembly (2014), *Thematic study on the right of persons with disabilities to live independently and be included in the community: report of the Office of the United Nations High Commissioner for Human Rights*, A/HRC/28/37, 12 December 2014, para. 25.

implies not merely closing institutions. It encompasses developing a “range of services in the community [...] to prevent the need for institutional care”.⁴

FRA’s [three-part series dedicated to this topic](#), published in October 2017, looks at three important factors in making deinstitutionalisation a reality: [commitments and structures](#), [budgeting and financing](#), and [measuring outcomes for persons with disabilities](#). Taken together, the three reports provide important insights that can support ongoing efforts to make independent living a reality for persons with disabilities.

⁴ European Expert Group on the Transition from Institutional to Community-based Care (2012), [Common European Guidelines on the Transition from Institutional to Community-based Care](#), p. 27.



Part I: Commitments and structures

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

Realising the right of persons with disabilities to live independently and be included in the community requires implementing meaningful and sustainable deinstitutionalisation. FRA evidence shows that one crucial starting point is a strategy on or covering deinstitutionalisation. Previous FRA opinions call for disabled persons' organisations to be closely involved in developing such policies.⁵

FRA opinion 1

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

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

FRA opinion 2

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

FRA opinion 3

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

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

⁵ FRA (2016), *Fundamental Rights Report 2016*, Luxembourg, Publications Office.

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

FRA opinion 4

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

Deinstitutionalisation requires that the phasing out of institutional services be coupled with developing accessible support services in the community. This entails a cross-sectoral approach that integrates both specialised services for persons with disabilities and general services available to the local community as a whole. Deinstitutionalisation is also likely to require developing new and innovative support services that are adaptable to individual needs.

FRA opinion 5

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

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



Part II: funding and budgeting

- A fundamental shift in how services for persons with disabilities are funded is needed to realise the right to independent living for persons with disabilities in practice. This includes redirecting investment from institutions to personalised services in the community that persons with disabilities guide and control.
- European Structural and Investment Funds (ESIF) play an important role in supporting deinstitutionalisation in many EU Member States. Some funding has, however, previously been spent on renovating existing institutions or building new institutions.
- For the 2014–2020 funding period, the EU has introduced measures to ensure that ESIF support deinstitutionalisation, in particular conditions that must be fulfilled before funds can be spent (so-called *ex ante* conditionalities). Civil society has a crucial role to play in formal and informal monitoring of the use of the funds to ensure that these measures are applied in practice.
- Various levels and sectors of government share responsibility for funding deinstitutionalisation and community-based services. The involvement of a complex mix of public authorities, sources of funding and types of service providers can result in regional disparities in service provision within Member States.
- Many Member States continue to invest considerable resources in institutions for persons with disabilities. This does not promote the goal of independent living under Article 19 of the CRPD.
- Where deinstitutionalisation strategies are in place and accompanied by specific budget allocations, they can be a basis for targeted funding for the transition from institutional to community-based support.
- There is a lack of robust, comparable and timely data on budget allocations for services for persons with disabilities within individual Member States and across the EU. This impedes evidence-based policymaking and undermines efforts to achieve deinstitutionalisation.

All but one of the EU Member States, and the EU itself, have ratified the CRPD, committing themselves to achieving independent living for persons with disabilities. Realising this goal requires redirecting funding from institutional services to community-based services. Evidence that FRA has collected

indicates that there is a lack of comprehensive data on whether or not such a funding shift is under way in the EU Member States. However, examples indicate that many Member States continue to invest heavily in institutions for persons with disabilities.

FRA opinion 1

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

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

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

FRA evidence also shows, however, that realising the promise of these tools requires strengthening the monitoring of ESIF use and applying financial corrections where funds are misspent. The report follows the European Ombudsman in highlighting the important role that public authorities and independent bodies, including civil society, can play in providing the information necessary for effective monitoring and control of ESIF.⁶

⁶ European Ombudsman (2015), *Decision of the European Ombudsman closing her own-initiative inquiry OI/8/2014/AN concerning the European Commission*, Guideline vii.

FRA opinion 2

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

FRA opinion 3

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

FRA opinion 4

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

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

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

FRA opinion 5

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

FRA opinion 6

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

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

This report underlines the lack of robust, comparable and timely data on funding for deinstitutionalisation and community-based services. Such data gaps impede needs-based budgetary planning. They also restrict the ability of Member States to make the transition from institutional to community-based support a reality. Moreover, as FRA evidence shows, data gaps prevent Member States from showing meaningful progress in implementing Article 19 of the CRPD.

FRA opinion 7

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

Part III: outcomes for persons with disabilities

- Persons with disabilities living in the community experience worse independent living outcomes than persons without disabilities, across all the areas analysed in this report. This is particularly apparent among persons with more severe impairments and among those with a lower economic status.
- Persons with disabilities are less likely than persons without disabilities to feel that they are free to decide how to live their lives. They are also more likely to feel left out of society.
- Large numbers of persons with disabilities continue to live in institutions in EU Member States.
- Persons with disabilities are, on average, less likely to be satisfied with their accommodation in the community than persons without disabilities.
- A variety of community-based services are available to persons with disabilities in EU Member States. This includes some form of personal assistance in 22 Member States. Nevertheless, for many persons with disabilities living in the community, the help they receive with everyday tasks is not sufficient to meet their needs.
- Nearly half of persons with disabilities face difficulties in using common everyday services such as grocery shopping, banking, postal services, primary healthcare services and public transport.
- There is a lack of robust, comparable and timely data on independent living outcomes for persons with disabilities within individual Member States and across the EU. In particular, very little information is available about how many persons with disabilities live in institutions and their experiences. This impedes evidence-based policy making and undermines efforts to realise the right to independent living.

Article 19 requires that all persons with disabilities be able to choose where and with whom to live, on an equal basis with others. A range of appropriate living arrangements must be available in the community to realise this choice. However, persons with disabilities are less satisfied than other persons with their household accommodation, this report shows. This suggests a need to assess the suitability of housing stock and planning policies to better meet the accommodation requirements of persons

with disabilities, for example in terms of location, accessibility or disability-related adaptations.

Institutionalised settings inhibit persons with disabilities from exercising choice and control over their daily lives. To that degree, they are therefore incompatible with Article 19. This includes not having to resort to living in institutionalised settings because of a lack of viable alternatives. The FRA report *Choice and control: the right to independent living* highlights this.⁷

FRA opinion 1

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

FRA opinion 2

EU Member States should implement measures to end the institutionalisation of persons with disabilities. These include closing down existing institutionalised settings and stopping new admissions to them. These measures should be guided by evidence-based national deinstitutionalisation strategies and should draw on a comprehensive mapping of the status of deinstitutionalisation in the Member States.

Individualised, user-controlled support is essential to achieve independent living. It empowers persons with disabilities to be included in the community. This requires both that appropriate services be in place and that they respect the dignity and individual autonomy of persons with disabilities. There are gaps in the provision of community-based services in EU Member States and, where available, they are often not sufficient to meet users' needs, this report suggests.

⁷ FRA (2012), *Choice and control: the right to independent living*, Luxembourg, Publications Office.

Personal assistance services are particularly well placed to offer persons with disabilities choice and control over their support. However, such services are not available in all Member States, FRA evidence shows.

FRA opinion 3

EU Member States should ensure that adequate, good-quality and freely chosen personalised support for independent living is available for all persons with disabilities, irrespective of their impairment. 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.

Being able to access services and facilities for the general population, such as education, transport and housing, on an equal basis with others enables persons with disabilities to participate actively and meaningfully in the lives of their communities. Persons with disabilities are more likely than other persons to face barriers in accessing services that are commonly available to the public, this report shows. Making services responsive to the needs of persons with disabilities has major implications for the way services across different sectors are provided. This is particularly the case in terms of ensuring accessibility, equal treatment and non-discrimination.

One way to improve accessibility is to develop minimum standards and guidelines on accessibility, according to the FRA human rights indicators on the right to political participation of persons with disabilities.

FRA opinion 4

EU Member States should extend the prohibition of discrimination on the grounds of disability to cover the provision of goods and services available to the general public. They should also ensure that failure to provide reasonable accommodation is recognised as a form of discrimination. Reasonable accommodation includes modifications and adjustments that ensure that persons with disabilities can exercise rights on an equal basis.

The EU should urgently adopt the proposed European Accessibility Act to set minimum standards for the accessibility of key products and services in the EU. The EU legislator should also consider all avenues to ensure that the proposed Equal Treatment Directive is adopted swiftly. This will guarantee equal protection against discrimination on the grounds of disability in access to goods and services.

FRA opinion 5

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

Article 31 of the CRPD requires States Parties to “collect appropriate information, including statistical and research data” to enable policy makers “to formulate and implement policies to give effect to the [convention]”. In practice, there is a lack of robust, comparable and timely data on independent living outcomes for persons with disabilities, as this report shows. This restricts the ability of Member States to implement Article 19, because it impedes evidence-based policy making. Moreover, data gaps prevent Member States from demonstrating meaningful progress in achieving independent living.

FRA opinion 6

The EU and its Member States should collect and collate reliable, comparable and timely data on independent living outcomes for persons with disabilities. This data collection should incorporate persons with disabilities living in institutions. This could include collecting and publishing qualitative and quantitative data for applying human rights-based indicators, such as those that FRA developed on Article 19 of the CRPD. To improve accountability and transparency, these data should be publicly available.

FRA opinion 7

Eurostat and national statistical offices in the EU Member States should continue to work with international bodies such as the Washington Group on Disability Statistics to develop inclusive methodologies for collecting statistical data on the right to independent living. These methodologies should allow for disaggregation of data by the type and severity of impairment. Statistical data collection should facilitate the participation of all persons with disabilities, including those with severe impairments and those living in institutions.



EU Member States, and the EU itself have ratified the CRPD, committing themselves to achieving independent living for persons with disabilities. Doing so requires a meaningful and sustainable shift from institutional to community-based living arrangements. This publication summarises the findings from the three FRA reports focusing on different aspects of deinstitutionalisation. The first and second report highlight the obligations the EU and its Member States have committed to fulfil, and look at how funding and budgeting structures can turn these commitments into reality. The third report assesses to what extent Member States have implemented the right to independent living, focusing on the effect commitments and funds are having on persons with disabilities' daily lives. Taken together, the reports provide important insights that can support ongoing processes of change.

Further information:

For the full FRA reports *From institutions to community living*, see:

- *Part I: commitments and structures* <http://fra.europa.eu/en/publication/2017/independent-living-structures>
Easy-read: <http://fra.europa.eu/en/publication/2018/institutions-community-living-part-i-commitments-and-structures-easy-read>;
- *Part II: funding and budgeting*, <http://fra.europa.eu/en/publication/2017/independent-living-funding>
Easy-read: <http://fra.europa.eu/en/publication/2018/institutions-community-living-part-ii-funding-and-budgeting-easy-read>;
- *Part III: outcomes for persons with disabilities*, <http://fra.europa.eu/en/publication/2017/independent-living-outcomes>
Easy-read: <http://fra.europa.eu/en/publication/2018/institutions-community-living-part-iii-outcomes-persons-disabilities-easy-read>.

Other relevant FRA publications include:

- FRA (2014), *Indicators on the right to political participation of people with disabilities*, Online data explorer, <http://fra.europa.eu/en/publications-and-resources/data-and-maps/polpar?mdq1=theme&mdq2=212>.
- FRA (2012), *Choice and control: the right to independent living*, Luxembourg, Publications Office, <http://fra.europa.eu/en/publication/2012/choice-and-control-right-independent-living-and-its-summary> available in Danish, English, German, Greek and French, <http://fra.europa.eu/en/publication/2012/choice-and-control-right-independent-living-summary-report>

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

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Photo (cover): © AdobeStock (from left to right: Dan Race; Rawpixel.com; Dörr&Frommherz)
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Print: ISBN 978-92-9491-997-7, doi:10.2811/18449
PDF: ISBN 978-92-9491-995-3, doi:10.2811/208277