From institutions to community living: ensuring deinstitutionalisation for all

Article 19 of the UN Convention on the Rights of Persons with Disabilities (CRPD) sets out the right of persons with disabilities to live independently and be included in the community on an equal basis with others. In addition, principle 18 of the European Pillar of Social Rights states that “everyone has the right to affordable long-term care services of good quality, in particular home-care and community-based services”.[[1]](#footnote-1) Achieving this means ensuring that persons with disabilities living in institutional settings can transition to community-based services with support they choose and control. This process is called deinstitutionalisation.

Article 19 is clear that independent living is a right for all persons with disabilities. However, the European Union Agency for Fundamental Rights’ (FRA) fieldwork research on drivers and barriers of deinstitutionalisation shows that certain groups of persons with disabilities are often left behind in deinstitutionalisation processes. The box at the end of this factsheet gives more information about FRA’s research, which took place in Bulgaria, Finland, Ireland, Italy and Slovakia.

This factsheet explores the role of age and degree of impairment in the deinstitutionalisation process. Drawing on the views of participants in the FRA research, it shows that:

* Some stakeholders across all countries felt that deinstitutionalisation is not ‘suitable’ for two groups in particular: older people and those with more severe impairments.
* Deinstitutionalisation processes tend to start with people perceived as ‘easier’ to move into the community, with older people and those with severe impairments often left to the end.
* Younger people can help to drive deinstitutionalisation processes. However, the transition from childhood to adult living arrangements remains challenging.

Participants identified negative attitudestowards deinstitutionalisation for particular groups, and the lack of adequate services available in the community as the most significant barriers to achieving deinstitutionalisation for all. The lack of adequate and appropriate community-based services is a major barrier to deinstitutionalisation overall, but is particularly acute for older people and those with severe impairments. Overcoming these barriers requires deinstitutionalisation processes that include measures to address the particular situation of older people and people with complex needs, participants highlighted.

# Age

Achieving independent living in the community entails approaches that adapt to changing needs across the lifecycle. Participants in the FRA research identified specific challenges facing both young people and older people. These are often concentrated around transition points – when a child with disabilities turns 18 or a young adult wants to leave their childhood home, or as adults with disabilities age.

FRA’s research did not look specifically at deinstitutionalisation for children, and no children were interviewed. However, many participants discussed the specificities of deinstitutionalisation for children and, in particular, young adults.

## Younger people with disabilities

* A lack of appropriate community-based services often forces young adults with disabilities to enter institutions or to remain in the family home.
* Changes in attitudes and education means that young adults with disabilities are more likely to be aware of their right to live independently and to advocate for it.

The right to live independently has a specific meaning for children under the age of 18, who should remain with their families whenever possible. The UN Convention on the Rights of the Child requires States to ensure that children are not separated from their parents against their will. Both the Committee on the Rights of the Child and the Committee on the Rights of Persons with Disabilities have urged States to support children with disabilities to live with their family, extended family or in foster care.

Participants in the FRA research focused on about the lack of options for young people when they turn 18. In some cases, the absence of appropriate community-based services for adults with disabilities can leave people feeling that there is little alternative to moving to an institution. For others, the lack of appropriate support in the community means remaining in their parents’ home well into adulthood.

In both situations, the lack of support is compounded by paternalistic and overprotective attitudes towards people with disabilities. Family members and service provider staff participating in the research often referred to adults with disabilities 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)

However, some participants felt that more young people with disabilities, particularly those educated in mainstream schools, are starting to claim their rights and campaign for adequate community-based services.

## Older people with disabilities

* Some participants, particularly service provider staff, expressed concern that long-term residents of institutions would find it challenging to adapt to life in the community.
* There is a lack of appropriate community-based services for people whose impairment is compounded by age-related disabilities.

In some Member States, residents of institutions for people with disabilities are typically older people with disabilities, as younger people either do not enter institutions or undergo deinstitutionalisation earlier. This raises important questions about how to ensure deinstitutionalisation processes are inclusive of older people.

Several participants worried how older people with disabilities who had spent most of their lives in institutions would fare during deinstitutionalisation. Support staff in Finland felt that the institution had become its residents’ ‘home’, and that requiring them to move would not necessarily be the right thing to do. This is closely linked to the consequences of long-term institutionalisation, including learned dependence on the support provided there. In one institution in Ireland, for example, some of the remaining residents originally moved there after being diagnosed with epilepsy. The manager of the service felt that their disability was primarily a result of decades of institutionalisation rather than their diagnosis.

Other participants argued that people who have spent long periods in institutions are particularly deserving of the opportunity to experience life in the community before the end of their lives.

The second major issue is the lack of community-based services responsive to the specific needs of older people. Participants in Bulgaria highlighted that persons with disabilities living in the community typically rely heavily on support from family members. Older people may not have living relatives, leaving them with little alternative but to remain in the institution:

*“[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)

In other cases, insufficient community-based services for older people can force those who have lived in the community, either their whole lives or since leaving an institution, to (re)enter institutions. Finally, previous FRA research shows that there are a number of inequalities in the way pre-existing and age-related disabilities are supported. There may be age requirements for access to support services that enable older people to live independently, for example.[[2]](#footnote-2)

Questions also arise about the coherence of policy for persons with disabilities and older persons. While many Member States are implementing deinstitutionalisation strategies for persons with disabilities, older people continue to enter ‘care homes’ or ‘old people’s homes’. In Finland, for example, older people with severe intellectual disabilities are moving from an institution for people with disabilities to care homes for older people. Several service provider staff in Ireland recounted difficulties ensuring that persons who had left the institution could remain in their own homes.

*“[National policy doesn’t] take into consideration the fact that it’s an aging population. […] A number of our ladies will ask us […] ‘you won’t send me back in’, and it’s awful really.”* (Ireland, service provider)

This prompted some participants to call for an increased focus on community-based services for older people within the scope of deinstitutionalisation efforts.

*"Deinstitutionalisation should at some point also touch institutions for seniors. It must be said that hand in hand with DI, we need to talk about community-based services, their development and their support. Actually, this is still a stumbling block that there is still a large amount of money that continues to flow into the residential services due to the fact that there is a large group of seniors and the willingness to change the flow towards the community services is small to none."* (Slovakia, a representative of a non-governmental organisation)

# Severity of impairment

* People with severe impairments face particular stigma impeding their opportunities to live in the community.
* A lack of appropriate community-based services means some participants conclude that deinstitutionalisation is not ‘suitable’ for people with severe impairments.

FRA’s research indicates that persons with less severe impairments tend to be the first to transition to the community, while those with more severe impairments are left until the end. One contributory factor is the particular stigma attached to people with severe impairments, and those with intellectual and/or psychosocial disabilities. A number of participants felt that deinstitutionalisation is not appropriate or achievable for persons with severe – particularly intellectual – impairments. In Finland, for example, one employee argued that a relatively remote institution is more appropriate for those with so-called ‘challenging behaviour’.

Some participants also highlighted factors that make deinstitutionalisation for persons with severe impairments more challenging, in their view. The most commonly cited is the lack of services in the community for those needing more intensive support. This can result in a situation where key services are only available in institutional settings:

*“Based on my experience, I would not [recommend deinstitutionalisation to] just anybody, because again, they have everything they need at the institution, especially the physiotherapy. […] You don´t have the kind of conditions at the apartment that you have at the institution.”* (Slovakia, employee of social service)

Several participants mentioned difficulties in understanding the preferences of people with severe impairments, particularly those that are non-verbal. This underlines the importance of developing appropriate supported decision-making structures.

Other participants focused on an absence of sufficient financial resources. One Irish participant expressed frustration that a proposal to build a home for a small group of people with severe impairments was rejected as too expensive. Another noted:

“*People with higher needs of support are resource intensive and until we come to the point where we accept that, we’re always going to have problems*.*”* (Ireland, national Article 33(2) monitoring body)

However, service provider staff also pointed to the often immediate and significant improvements in the quality of life of people with severe impairments who move to the community:

“*We have moved a lot of people into community settings that have really very heavy support needs. […] Very often there isn’t […] marked evidence of […] independence but there is very often an immediate improvement in terms of the personal stress levels.”* (Ireland,manager of a service provider manager)

**FRA’s local-level research on drivers and barriers of deinstitutionalisation**

FRA wanted to contribute to making implementation of deinstitutionalisation more effective by capturing 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 policy makers, to persons with disabilities, and the staff of institutional and community-based services – the opportunity to share their knowledge and experience of what drives the process forward, and the barriers that hold it back.

The main results of this research are presented in the report FRA (2018), [*From institutions to community living for persons with disabilities: perspectives from the ground*](https://fra.europa.eu/en/publication/2018/independent-living-reality)*.*

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1. European Pillar on Social Rights, Principle 18, <https://ec.europa.eu/commission/priorities/deeper-and-fairer-economic-and-monetary-union/european-pillar-social-rights/european-pillar-social-rights-20-principles_en>. [↑](#footnote-ref-1)
2. FRA (2018), [*Shifting perceptions: towards a rights-based approach to ageing*](https://fra.europa.eu/en/publication/2018/frr-2018-focus-rights-based-ageing), Focus report. [↑](#footnote-ref-2)