From institutions to community living for persons with disabilities: key milestones

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. 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.

Research by the European Union Agency for Fundamental Rights (FRA) in five EU Member States identified four key milestones common to different deinstitutionalisation processes. This factsheet outlines these milestones and reflects on the implications for policymakers responsible for designing and implementing the transition from institutional to community-based support for persons with disabilities. 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.

**Figure 1: Key milestones in the deinstitutionalisation process**

*Source: FRA (2018)*

FRA’s research indicates four milestones that typically characterise deinstitutionalisation processes (see Figure 1):

* Research participants reported that progress towards deinstitutionalisation is often very slow until the **first win** is achieved.
* The first win is typically followed by a small acceleration in the speed of deinstitutionalisation. However, it is only after reaching a **tipping point** that deinstitutionalisation proceeds more rapidly, participants said.
* Deinstitutionalisation processes then often reach **the hump** when, participants noted, the final stages of closing down an institution prove particularly difficult.
* Many participants expressed concern that some community-based living arrangements retain institutional characteristics and become ‘mini institutions’. This prompts the need for a **second wave** of deinstitutionalisation where people transition to personalised support that they choose and control.

Finally, it is important to recognise that deinstitutionalisation is not itself an end goal. Rather, it is one element of broader efforts to ensure that persons with disabilities can enjoy their right to live independently and be included in the community. Securing independent living is an on-going challenge, which needs to respond to people’s changing needs over time to ensure that they have appropriate housing and support to ensure community integration throughout their lives.

# The first win

The first win is a successful initial, often small-scale, example of deinstitutionalisation. It can be a successful pilot project, or the first success story in a larger deinstitutionalisation process. Participants highlighted its importance in providing the positive examples that are a key driver of successful deinstitutionalisation. Such success stories can inspire and reassure people involved in the deinstitutionalisation process, including policymakers, service providers, people with disabilities and their families, and local communities:

* In Italy, families who had initial concerns about their relatives with disabilities’ ability to live outside an institution saw their relatives’ skills and independence develop in community-based settings. They became active champions of the process.
* Institutions make people with disabilities less visible, which can prompt distrust and even fear of among members of local communities where deinstitutionalisation is taking place. In Bulgaria, the opening of group homes for children leaving institutions provoked protests from local residents. When the project went ahead, however, good relations developed between residents with disabilities and their neighbours. Some residents earned casual income doing odd jobs for their neighbours, and several neighbours called by the group homes to chat.

Many participants emphasised the importance of achieving a first win in the local area, as positive stories from close to home have the greatest impact: “*families were a bit like that’s grand in America, and it’s grand in Australia, but this is Ireland”* (Ireland, service provider).

## Policy implications

FRA’s research shows that first wins are important irrespective of the approach to deinstitutionalisation, as they demonstrate the benefits that it can bring for those involved:

* Where deinstitutionalisation is led by national or regional authorities, first wins show that policy goals are attainable in practice, and encourage buy in at the local level.
* Where local actors are driving deinstitutionalisation, the first win gives others something to emulate and confidence that it can be achieved.
* Concentrating on achieving a first win can allow actors to move swiftly, and not get caught up in lengthy preparations for full deinstitutionalisation.

Participants stressed that a focus on first wins should not distract from the overall goal of achieving deinstitutionalisation for all. Following the first win, they argued, deinstitutionalisation measures should scale up rapidly to move towards the tipping point.

# The tipping point

*“Suddenly when people started moving, when the staff could see a future and could see something much, much better in terms of quality of life for the people they were working with, the whole thing seemed to turn.”* (Ireland, senior manager of a service provider)

Many participants described a tipping point in the deinstitutionalisation process, when most of those involved accept the transition to the community as the new ‘norm’. After the tipping point, the process moves much more quickly. Participants tied reaching the tipping point to a change in attitudes among those involved in deinstitutionalisation – one of the key factors of successful deinstitutionalisation processes identified by the FRA research:

* People with disabilities are empowered to demand better living situations.
* Families’ fears for the safety and security of their family members in the community ease.
* Staff of institutions overcome concern about the security of their employment and the safety of their clients. They come to understand that deinstitutionalisation is best for the people they serve. As one employee noted: *“first of all we have to change since we work with them. After that, I think the change will spread.”* (Italy, employee of a community-based service)

This change in attitudes can occur in different ways. Giving staff and management the opportunity to learn from deinstitutionalisation processes elsewhere can be key:

“*When we met with people from the Czech Republic who used concrete examples to [show employees] why the existing system was not good, that was basically the moment when tables began to turn, bit by bit. […] [The employees] began to [realise] that it really made sense for the clients to see the quality [of provided services] increase. And this information began to change them.”* (Slovakia, regional policymaker)

In addition, strong commitment to deinstitutionalisation among senior management or in the wider community can help the process reach the tipping point.

## Policy implications

The sustained momentum required to reach the tipping point has implications for the funding of pilot projects or the first stages of deinstitutionalisation processes. It highlights the importance of a plan for when the pilot project or initial deinstitutionalisation measures end. Financing from the European Structural and Investment Funds (ESIF) supports the development of new community based services in a number of EU Member States. However, FRA research suggests there is often a gap between the end of the pilot project and the start of national funding for the service. Even where national financing is available, it is often not sufficient to maintain previous quality standards.

Participants signalled that reaching the tipping point requires evidence-based, long-term planning backed by full commitment to deinstitutionalisation, including in terms of financing. It also means proactively building on initial successes.

# The hump

After the tipping point, the momentum generated can allow deinstitutionalisation efforts to move quite quickly. Participants noted, however, that final stage of closing an institution can be particularly difficult, creating a hump in the deinstitutionalisation process. They highlighted several challenges:

* Lack of community-based services responsive to the needs of people with severe impairments or complex needs. This means both they are often the last to leave the institution, and that their move into the community is delayed.
* The costs of ‘double funding’ as both the remaining institutional and the developing community-based services run simultaneously.
* Resistance among some staff, family members and persons with disabilities to leaving the institution, particularly when they have lived or worked there for long periods.

*“And that’s why, I think, we’re coming to the end now because we’ve a cohort of staff here who won’t want to move. We’ve a cohort of service users who won’t want to move and sometimes you’ll have the staff getting to the families and so you have to unpick all of that.”* (Ireland, service provider)

## Policy implications

The Office of the UN High Commissioner for Human Rights has indicated that ‘double funding’ is necessary during the deinstitutionalisation process.[[1]](#footnote-2) Participants highlighted that this requires the allocation of sufficient funds in national budgets. However, they also emphasised that maintaining parallel systems should be a short term solution, and that efforts should focus on developing community-based services that are responsive to the needs of all persons with disabilities.

Overcoming the ‘hump’ also involves changing the attitudes of those who remain opposed to deinstitutionalisation. For staff, this often requires addressing fears with regard to job security and working conditions. Given that the last residents of an institution are frequently older people and those with more severe impairments, it also means recognising that independent living is a right for all, irrespective of age and degree or type of impairment.

# The second wave

Some participants spoke about a second wave of deinstitutionalisation, in which persons with disabilities gain greater choice and control over their living arrangements and support services than when they first left the institution. This can happen for two main reasons:

* People with disabilities first move to settings with additional support after leaving the institution in order to build up everyday living skills. The FRA research highlighted instances where residents who were initially fearful of deinstitutionalisation gained confidence and independence on moving to a group home. They then pushed for personalised support and housing to enable them to live more independently.
* The community-based services initially established for people leaving institutions retain many characteristics of institutions. A transition to more personalised services is therefore needed to realise independent living. In Finland, for example, many people with disabilities moved from institutions to group homes with 15 or more residents, much larger than a typical house. In Ireland, group homes have reduced in size from 6-8 to 2-3 persons.

Some research participants felt that a two-step deinstitutionalisation process is more likely to succeed as it enables persons with disabilities to receive additional support and build up new skills during a more gradual transition. However, others felt that a two-step approach both distracts from reaching the goal of independent living and wastes limited resources. In Bulgaria, for example, representatives of the independent living movement expressed concern that the community-based services now being built risk perpetuating institutional care in smaller settings and that a more individualised approach should be taken from the outset.

## Policy implications

Many participants highlighted the importance of ensuring that sufficient and appropriate support is available for those who first moved to in group homes but now wish to live more independently. One participant with a disability recounted how she moving from a group home to an apartment shared with a close friend. However, a lack of support to navigate difficulties with the landlord meant that they had little choice but to return to a group home.

Participants also emphasised that there is no one ‘solution’ to achieving independent living. Individuals each have different needs, and those needs change as people’s circumstances alter over time. This underlines the importance of policy actions that are both flexible and responsive to the needs of people with disabilities.

**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. 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. [↑](#footnote-ref-2)