From institutions to community living for persons with disabilities:

community-based housing arrangements

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

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.

One of the key issues emerging from the European Union Agency for Fundamental Rights’ (FRA) fieldwork research on drivers and barriers of deinstitutionalisation is the importance of available and appropriate housing for persons with disabilities in the community. This factsheet outlines some of the main types of living arrangements available to people leaving institutions encountered in FRA’s research. It then identifies four key elements of establishing living arrangements in the community that promote and enable independent living. 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.

Persons with disabilities and their families, staff working in disability services, and national and local policymakers participating in the research all distinguished between the physical and cultural aspects of accommodation in the community (see figure 1). Physical characteristics include the size and location of living arrangements; cultural characteristics relate to the way services are provided.

**Figure 1: Physical and cultural characteristics of community-based services promoting independent living**

*Source: FRA (2018) based on stakeholder views*

# Housing arrangements available to people leaving institutions

Official statistics on deinstitutionalisation focus on how many people are leaving institutions, rather than where they are moving to. Participants in FRA’s research highlighted some common types of housing arrangements for people moving into the community.[[1]](#footnote-1) There is, however, a wide range of community-based services for persons with disabilities in the EU, as FRA’s overview of types of institutional and community-based services indicates.[[2]](#footnote-2)

## Group homes

Group homes typically accommodate larger numbers of people than is common in the general population. In Finland, for example, many people leaving institutions have moved to group homes with 15 or more residents. Group homes created to support the deinstitutionalisation of children in Bulgaria also house 15 or more young people, and the 2018 Action Plan for the deinstitutionalisation of adults indicates a similar approach.[[3]](#footnote-3)

In group homes, support is generally tied to the living arrangement. This creates the risk that services are designed to promote the efficient functioning of the group home rather than to meet the individual needs of its residents. Participants reported that some group homes have the characteristics of an institution, albeit in a smaller setting. These include: curfews, scheduled mealtimes and a focus on common, rather than individual, activities. This prompted a number of participants to indicate that group homes do not enable independent living. They called for a ‘second wave’ of deinstitutionalisation to enable people to leave group homes for more individualised living arrangements.

Despite this, several persons with disabilities participating in the research appreciated the greater space, privacy and freedom of group homes. They contrasted the possibility to invite friends over and to leave the group home with the situation in the larger institutions they previously lived in. These positive views may reflect the absence of alternative housing options offering greater choice and control.

## Clustered communities

Cluster style housing typically involves the provision of houses for people with disabilities on a specialised campus or in a specific housing estate or street.[[4]](#footnote-4) One arrangement in Italy consists of three apartments, each home to two people with disabilities. Residents have the keys to their own homes, and support is provided by a 24-hour concierge and an educator who visits for seven hours each day. Finland has established apartment blocks where residents with and without disabilities live in their own apartments, with different levels of support available for the residents with disabilities. One such building accommodates 15 residents with intellectual disabilities, and 21 residents without disabilities.

Participants had varying views on clustered housing. Some felt it hampers community integration by grouping people with disabilities together. Others credited it with enabling the provision of better support for residents, and helping to counteract loneliness and isolation. Participants felt that the intentional character of the apartment blocks for persons with and without disabilities mean that the residents with disabilities are surrounded by people who are open and welcoming towards them.

## Accommodation dispersed in the community

Participants also spoke about living arrangements in smaller homes dispersed throughout the community. Such ‘dispersed housing’ involves “apartments and houses of the same types and sizes as the majority of the population live in, scattered throughout residential neighbourhoods among the rest of the population”.[[5]](#footnote-5) Participants in Ireland identified two types of dispersed housing. In one type, housing and support are provided by the same service provider, with two or three residents sharing a standard family home rented by the service provider. In the other, people with disabilities are assisted to rent their own apartments, with personal support provided separately. In Italy, some with disabilities interviewed had succeeded in obtaining accommodation in social housing.

Participants with disabilities living in dispersed housing were generally very positive about it. However, several staff working in disability services expressed concern about the potential for loneliness and isolation. Moreover, this model is dependent on appropriate support being available in the community. In Bulgaria, for example, some participants moved from a group home to a rented flat of their own. However, they then had no support and little alternative but to return to a group home.

## Transitional housing

People living in institutions often lose, or do not develop, independent living skills. Overcoming the resulting ‘learned dependence’ is a major barrier to deinstitutionalisation, FRA’s research shows. This led some research participants to indicate that moving in a single step from a large institution into one’s own home is too much of a leap for many people with disabilities. They suggested that an intermediary step can help them prepare for life in the community.

Some participants saw group homes as offering such transitional accommodation. However, group homes are usually established as permanent places of residence, rather than as a stepping stone to housing offering greater independence. In contrast, the ‘training apartments’ found in Italy and Slovakia are specifically designed for this purpose. They provide living arrangements similar to those in the community, but generally with a higher level of support. This support aims to enable people with disabilities to develop the everyday skills needed for independent living in the community.

*“The director described the whole process to us: we would go to the training flat to learn all the skills necessary for independent living and, after that, we would move to a supported living flat, outside of the institution. […] We learned how to prepare food, wash our laundry, iron our clothes, how to count money, how to go to a shop and buy things, how to buy tickets for the train or bus.”* (Slovakia, person with a disability)

# Key elements of living arrangements enabling independent living

Four key elements emerged from the FRA research as ensuring that living arrangements enable persons with disabilities to live independently in the community. These closely mirror the main components of Article 19 of the CRPD.

*“I think, unfortunately, sometimes ‘community-based’ is sometimes looked at in terms of bricks and mortar, as opposed to looking at it in the context of the individual. The word community means connecting with community, living in a community.”* (Ireland, national stakeholder)

## Ensure choice and control over where to live

*“Article 19 is not properly implemented if housing is only provided in specifically designed areas and arranged in a way that persons with disabilities have to live in the same building, complex or neighbourhood.”* CRPD Committee (2017), [General Comment No. 5 (2017) on living independently and being included in the community](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/5&Lang=en), CRPD/C/GC/5, 27 October 2017, para. 34

Article 19(a) of the CRPD requires that “persons with disabilities have the opportunity to choose their place of residence […] on an equal basis with others and are not obliged to live in a particular living arrangement”. In practice, however, the FRA research indicates little choice of housing options for people with disabilities leaving institutions.

Participants identified several reasons for this, including: the high cost of housing, the scarcity of social housing stock, insufficient accessible housing, and obstacles linked to disability-related stigma and discrimination. Many managers of services and authorities felt that offering even one acceptable community living option presented a significant challenge. As a result, efforts often focus on identifying ‘the best’ community living option, rather than recognising that a range of options are needed to suit different individuals.

“*Lack of choice means that [the choice is] more or less take it or leave it. In those cases they don’t listen to you. So when the city makes some decision, you just have to live with it*.”(Finland, representative of a disabled persons’ organisation)

For many participants, one important way to ensure that persons with disabilities have equal choice over where to live is through access to social housing. Several barriers hampering this in practice, however. In many places, social housing is in short supply for the general population. People with disabilities face further specific challenges, particularly around accessibility. FRA’s recent report on independent living outcomes for persons with disabilities explores this issue in more depth.[[6]](#footnote-6)

Participants highlighted finding accessible housing for persons with physical disabilities as a significant challenge. In Bulgaria, participants with physical disabilities noted that they could apply for social housing on an equal basis with others, but were expected to pay for any accessibility adaptations. In Ireland, much social housing is in economically disadvantaged areas. Some participants were concerned that “*we are putting people who are already devalued into devalued areas”* (Ireland, local official). They felt that people with disabilities were at risk of becoming isolated and lonely in such situations.

## Ensure choice and control over whom to live with

Article 19(a) of the CRPD also requires persons with disabilities to have choice over who they live with. The research indicates that those transitioning to community-based living arrangements tend to have more choice and control over who they live with than where they live.

Most persons with disabilities participating in this research live with other people with disabilities. Those in dispersed or clustered housing have some level of choice over whom to live with. In group homes, however, participants reported little choice. Such living arrangements are likely to impede the possibility of developing intimate relationships or a family life.

Few participants with disabilities live in their own apartments. One recounted the bureaucratic difficulties and family resistance he faced when he and his fiancée wanted to get married and have their own flat. Ultimately, however: “*We made it. We got what we wished for, what we wanted.”* (Italy, person with a disability). He and his wife have a live-in support worker, and a part-time housekeeper.

## Separate support from housing arrangements

Article 19(b) of the CRPD requires States parties to provide a range of support services for persons with disabilities. This should not be tied to particular living arrangements:

*“Mandatory ‘package solutions’ which […] link the availability of one particular service to another, expect two or more persons to live together or can only be provided within special living arrangements are not in line with article 19.”* CRPD Committee (2017), [General Comment No. 5 (2017) on living independently and being included in the community](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/5&Lang=en), CRPD/C/GC/5, 27 October 2017, para. 17

In practice, however, personalised support separate from living arrangements was only available to a few research participants, and limited to people living either alone or with a partner.

Some participants felt that the solution is for social housing authorities to provide accommodation for persons with disabilities on an equal basis with the rest of the population. However, managers of support services for persons with disabilities suggested that they were better placed to ensure accessibility and appropriate support when they retained responsibility for housing. Until a better range of personalised support systems is available, they said, it is not possible to decouple housing and support.

Other participants highlighted the advantages of certain types of clustered housing options, which they felt make it easier to provide ‘light touch’ support. For instance, the clustered apartment scheme in Italy has a 24-hour building administrator who has received specific training. One family member noted that this person is: “*identified as a person of confidence in the building that they can rely on, but who is not actually responsible for them.”* (Italy, family member of a person with disabilities)

## Make services available to the general public fully accessible

*“[T]he closure of institutions […] in itself is not enough. Such reforms must be accompanied by comprehensive service and community development programmes.”* CRPD Committee (2017), [General Comment No. 5 (2017) on living independently and being included in the community](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/5&Lang=en), CRPD/C/GC/5, 27 October 2017, para. 17

Article 19(c) sets out the right to access community services and facilities on an equal basis. However, participants reported numerous physical and attitudinal barriers to accessing services, particularly health and transport services. Housing arrangements often have a significant impact on access.[[7]](#footnote-7)

Even if an individual’s housing meets their needs, the surrounding area may be inaccessible: *“people in wheelchairs [...] must struggle with bad pavements all over Slovakia, […] bad bus stops”* (Slovakia, person with a disability). In Ireland, much of the accessible housing stock is in the countryside, leaving persons with disabilities reliant on support workers to drive them around. Accessible housing in towns and cities can facilitate access to a much wider range of services, including employment, and cultural or social events. In Finland, one participant who had moved from a suburban group home to an apartment in the town centre emphasised how this enabled her to walk to where she does her hobbies.

Many participants reported that general health services are not sufficiently responsive to persons with disabilities, and that their health problems are often underplayed or ignored. Some felt that clustered accommodation, group homes or even – a few argued – institutions are better options for people with significant medical needs, as they enable access to more specialist and responsive healthcare.

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| **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. For more information types of services, see 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*](http://enil.eu/wp-content/uploads/2016/09/Guidelines-01-16-2013-printer.pdf)*.* [↑](#footnote-ref-1)
2. European Union Agency for Fundamental Rights (FRA) (2017), [*Summary overview of types and characteristics of institutional and community-based services for persons with disabilities available across the EU*](http://fra.europa.eu/sites/default/files/fra_uploads/2017-10-independent-living-mapping-paper_en.pdf), Luxembourg, Publications Office. [↑](#footnote-ref-2)
3. Bulgaria, Council of Ministers (2018), *План за действие за периода 2018-2021 г. за изпълнение на Националната стратегия за дългосрочна грижа* (Action Plan for the period 2018–2021 for the implementation of the National Strategy for Long-term Care), Council Decision 28 of 19 January 2018. [↑](#footnote-ref-3)
4. Ireland, Health Service Executive (2011), [*Time to Move On from Congregated Settings: a strategy for community inclusion*](https://www.hse.ie/eng/services/list/4/disability/congregatedsettings/time-to-move-on-from-congregated-settings-%E2%80%93-a-strategy-for-community-inclusion.pdf). [↑](#footnote-ref-4)
5. *Ibid*., p. 72. [↑](#footnote-ref-5)
6. FRA (2017), [*From institutions to community living: Part III: outcomes for persons with disabilities*](http://fra.europa.eu/en/publication/2017/independent-living-outcomes)*,* Luxembourg, Publications Office*.* [↑](#footnote-ref-6)
7. FRA (2017), [*From institutions to community living: Part III: outcomes for persons with disabilities*](http://fra.europa.eu/en/publication/2017/independent-living-outcomes)*,* Luxembourg, Publications Office*.* [↑](#footnote-ref-7)