

# Q+A: Time to Move On From Congregated Settings

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## What is the project “Time to move on from Congregated Settings” about?

In 2012 the *Time to Move on From Congregated setting: A Strategy for Community inclusion* report was published. The report recommended that people with disabilities living in institutional settings should be supported to move to homes in the community.

The Time to Move on project is supporting people with disabilities to move in line with the recommendations of the report.

## What is a congregated setting and how many people with disabilities live in congregated settings in Ireland?

The report defined congregated settings as ‘... where ten or more people with a disability are accommodated in a single living unit or where people are placed in accommodation that is campus based.’

The report found that in most cases, the people in congregated settings lead isolated lives, away from their community and from their families. Many people experience living conditions where there is a lack of basic privacy and dignity. At the time the report was written over 4,000 people lived in congregated settings.

## What is the vision for people with disabilities since the Time to Move On project has started?

The report recommended that the people currently living in congregated settings should be supported to move or **transition** to a new model of community based supports where they can live in houses in their communities connected to their family and friends. This move is called a transition, because the way the person is supported will also change, it is not just about moving home.

Work is on-going to support people to transition from living in congregated settings to more appropriate homes in the community. The vision of the Time to Move On report outlines that:

- Each person will be supported to choose where and with whom they live and a person centred planning approach will be taken to enable each individual to choose how they will be supported
- That no more than four persons with disabilities should live together in a home in the community and that ideally homes are not clustered together. New homes for people with disabilities are now planned in line with these recommendations.
- Each person who moves will have the same entitlements to mainstream community health and social services as any other citizen. They will have the supports they require to live as independent a life as possible as an equal citizen of the state.

### **How is the project being implemented?**

The HSE National Service Plan sets a specific target for the number of people that will be supported to move every year. This helps to drive the change and ensure people are being supported to transition to live in their community.

A Service Reform Fund established from a partnership between the Atlantic Philanthropies, Department of Health, HSE and Genio Trust is supporting innovative projects in a number of congregated sites. These projects are supporting the move away from traditional and congregated services to more person-centred approaches.

A person-centred approach is where the needs and wishes of the individual are kept at the centre of all of the decisions made about their care.

### **Where will people live and who will decide?**

Service providers are supporting those living in congregated settings to decide where they want to live and who they want to live with. Decisions on how this will happen for each person will be made in consultation with the person and their family, once this is in line with the person's wishes. While many people are sharing their home with others, some people are being supported to live alone.

The service provider will take responsibility for sourcing a person's new home and as outlined below there are several options available. People will be supported to understand their choices and what is involved. Where possible and appropriate, people will be supported to hold a tenancy agreement in their new home.

## **What kind of housing are people moving to?**

People are being supported to access a range of different homes. Some people are renting homes from private landlords or they are being allocated housing by the local authority or approved housing body.

Houses are also being purchased or newly built to accommodate the people moving from the congregated settings. Some homes are being funded by the Department of Housing, Planning and Local Government and provided through local authority housing and Approved Housing Bodies. The HSE Estates department are also providing new homes for people with disabilities. They have produced a number of videos that showcase new homes developed for residents moving from congregated settings. These videos can be seen at:

<https://youtu.be/gNj49zM4wNw>

<https://youtu.be/CrGQ3i9o2Yc>

<https://youtu.be/Da0zITPoQzw>

## **Who will support people who move to community homes?**

Each service provider will engage with the person and their family, where this is in line with their wishes, to determine what arrangements will be put in place, to support the person in their new home. In some cases, staff from the current residential setting will continue working with the person as they move into the community and in other cases there will be new support staff, or a mixture of both new and old staff.

People moving to their own home will receive the support they require to ensure they are safe and living the life of their choice. Their service provider will continue to regularly review the support arrangements for each person to ensure that they are meeting the person's needs.

Over time, each person will be supported to explore their own interests and choices and will be supported to live, to connect and to actively participate in their local community. People will also be supported to access community health services i.e. their own GP, the local pharmacy, public health nurse.

## What supports are available to families, service providers and organisations who are supporting people to move to a new living arrangement?

There are a range of information resources and documents available that provide information and guidance on making the move to community from congregated settings. These include:

*For Residents / families:* [www.hse.ie/timetomoveon](http://www.hse.ie/timetomoveon)

- An Easy Read version of the Time to Move On report
- Information sheets on the policy for Families, Staff, Public Representatives, Senior Managers & Board Directors
- Articles and Videos representing the voices of residents, their families, staff and managers

*For Service Providers*

- Communication Key Messages
- Communication Stakeholder Mapping tool
- **Community Living Transition Planning Toolkit** A guide for service providers on the process of supporting each person to develop their plan to move into the community.
- **Project Action Plan** A tool for service providers to plan for decongregation and development of a community service.
- **Supporting People with Disabilities to Access Appropriate Housing in the Community** A guidance document that provides an overview of the process of determining a person's housing preferences, outlines social housing support options and information on securing and accessing accommodation.
- **Making A Home: A practical guide to creating a home and moving to the community** This guide maps the practical steps from the time a home is selected through to when the person moves in, essentially the process of "making a home".

## What is the timescale for moving people out of congregated settings?

The original report proposed that nearly all of the people with disabilities in congregated settings would move to housing in the community within seven years.

It is taking longer than first thought to close all of the congregated settings but remains a Government priority. **A Programme for a Partnership Government** stated:

*'As part of our commitment to equality of opportunity, we will support people with disabilities in maximising their potential, by removing barriers which impact on access to services, education, work or healthcare. We will move people with disabilities out of congregated settings to enable them live independently and be included in the community...our objective is to reduce this figure by at least one-third by 2021 and to ultimately eliminate all congregated settings.*

The Time to Move on project continues to be a priority for the HSE.

### **What progress has been made to date?**

When the report was written over 4,000 people lived in congregated settings. By 2019 the number has reduced to fewer than 2,000 people. Thirteen institutions have fully closed and many of the larger congregated services have supported significant numbers of people to transition. This has also led to improved living conditions for the people who still live in congregated settings as many people now have more personal space and privacy.

### **The people who have moved - their stories**

For many people their lives have changed significantly following their move to the community. A number of stories have been captured on video which can be seen [here](http://www.hse.ie/timetomoveon) [www.hse.ie/timetomoveon](http://www.hse.ie/timetomoveon) and their stories can be read [here](#). Many of the reports on the progress under the Time to Move on policy contain case studies and can be viewed [here](#).

<https://www.hse.ie/eng/services/list/4/disability/congregatedsettings/reports-and-publications/>

A number of videos also capture the views of family members, staff and service managers that have been involved in transitioning and these can be viewed on the Genio website [www.genio.ie/videos](http://www.genio.ie/videos) and on the Time to Move on webpage [www.hse.ie/timetomoveon](http://www.hse.ie/timetomoveon)

### **What is the impact of the policy so far in Ireland?**

The National Disability Authority (NDA) is undertaking a large study which is exploring the quality of life outcomes for people who are "Moving In" to homes in their communities. People are being interviewed before they move and again 6 to 9 months after they move to their new homes in the community.

The NDA provided an update on the project which was included in the Review of the Policy Implementation 2012-2017 and the NDA confirmed that *"Overall the results to date indicate very positive improvements in*

*quality of life for those who have made the move to the community” .*

The update can be read [here](#).

<https://www.hse.ie/eng/services/list/4/disability/congregatedsettings/reports-and-publications/>

In July 2019 HIQA published a report: *Five years of regulation in designated centres for people with a disability* which looks at the first five years of statutory regulation of designated residential centres for people with disabilities in Ireland. The report includes a number of comments on the impact of people moving from congregated settings to new homes in the community and a number of case studies detail the journeys that services and service users have taken in transitioning to community based homes, with some very positive outcomes for residents.

The full report is available here <https://www.hiqa.ie/reports-and-publications/key-reports-and-investigations/five-years-regulation-designated-centres>.

## **Are there examples of other countries that have made this change?**

The Fundamental Rights Agency (FRA) which is a European Agency that helps to ensure that the fundamental rights of people living in the EU are protected looked at deinstitutionalisation – moving people from institutions to the community – across a number of countries in the European Union. The FRA went to a number of countries where they spoke to people with disabilities, their families, support workers and politicians. They asked people what it is like to live in an institution and the community and explored what does and does not work on the ground.

They produced a report *From institutions to community living for persons with disabilities: perspectives from the ground*. This report

[https://fra.europa.eu/sites/default/files/fra\\_uploads/fra-2018-from-institutions-to-community-living-ground-perspectives\\_en.pdf](https://fra.europa.eu/sites/default/files/fra_uploads/fra-2018-from-institutions-to-community-living-ground-perspectives_en.pdf) gives a voice to people with disabilities themselves, giving direct testimony about the “transformational power of deinstitutionalisation.”

The report contains case studies in which some people that have already made the move from congregated settings tell their story about how the improvement in the quality of their life since they moved on. The report finds there are real benefits for people who move from institutional living to supported living in the community.