



Briefing Note for Family Members

What is the Time to Move on from Congregated Settings policy?



The *Time to Move on from Congregated Settings - A Strategy for Community Inclusion* report was published and adopted as national policy in 2012. This report found that in Ireland over 4,000 people with disabilities were living in congregated settings, ‘where ten or more people reside in a single living unit or are campus based’. The report found that many people in these settings spent their lives apart from their families and their communities without basic privacy and dignity that they would have living in their own home.

The policy recommends a person-centred approach where every person is enabled and supported to lead the life they want. This is line with international evidence, with new models of residential services now being developed so that people with disabilities will be supported to live “ordinary lives in ordinary places”.

Under the policy, people living in congregated settings now have the opportunity and the right to move to a home of their choice in the community. Each person will be supported to explore their own interests and choices and will be helped by family, supporters and friends, a network of local community contacts with the on-going support of their current service provider. This will enable people to choose where and with whom they live and to lead the life of their choice and to take part in activities in their local community.

In Ireland there are around 2,200 people still living in congregated settings, but over 6,000 people live in homes in their communities.

In 10 counties in Ireland, there are no congregated settings, and all residents live in Community houses, with on-going support.

Every person can have their support needs met within community residential services.

It's lovely to have your own home, your own place...without some telling you do this or do that... it was never my home and this is my home, ... I decide, like what to eat, when to get up; yes I decide who comes in my front door... I can come and go as I please, go to bed when I like and my visitors can come and I can make tea.

Rosaleen: who moved to her new home after 50 years in a congregated setting

...a person-centred approach that will ensure each individual is enabled and supported to lead the life they want...



Transforming Lives

Programme to Implement the Recommendations of the “Value for Money and Policy Review of the Disability Services in Ireland” report

Consultation
Communication
Engagement
Listening
Involvement
Sharing Ideas



... Time will be taken with each person to support them to discover what a pace that suits them and allows them to be fully involved...

Leading a Good Life....



.... ordinary lives in ordinary places

I'm a family member of a person who lives in a congregated setting and I have some questions....

What say do I have as a family member in planning a move for my relative?

The person themselves will always be consulted first in relation to what they would like. As a family member you will be consulted and involved once this is in keeping with your relative's wishes and this could include:

- Decisions about how your relative will be supported
- Decisions about who a person may wish to live with, where they will live and the type of home they will have
- All other significant decisions on an on-going basis

How will the move to community be planned?

Each person who is moving will be at the centre of the decision making process in relation to where they live, who they live with, the type of house they will live in and how they will be supported.

Supporting a person to move from a congregated setting to a new home in the community is not something that happens overnight. Time will be taken with each person to support them to discover what they want at a pace that suits them and allows them to be fully involved. Taking time in this way is important, as it can be a challenge for the person with a disability to make decisions, particularly when their own experiences which will influence their choices may have been limited.

Each service provider is developing a plan to identify how they are going to support people who are currently living in congregated settings to move to homes in the community. As the plan is being developed service providers will engage with individuals and their families to involve them and to ensure people are aware of the progress being made.



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How will decisions on where my relative lives be made and who will be involved?



A new home

Our inspectors have seen many positive examples where such a transition has resulted in significant improvements in people's lived experience in residential care."

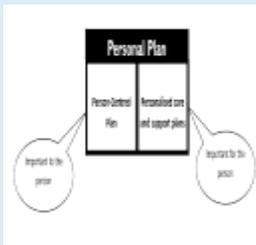
Overview of HIQA's regulation of social care and healthcare services in 2017

Decisions on the housing arrangement for each person will be made in full consultation with the person and their families once this is in line with the person's wishes. The service provider will take responsibility for sourcing a person's new home. The house may be purchased, rented, leased or it may be a purpose built home. The house may be owned by an Approved Housing Body, a local authority, a private landlord or the HSE. People who can understand what is involved will be supported to hold a tenancy agreement in their new home.

Each person moving to their new community home will be supported to live how they chose. A person may choose to live alone, with friends or with family. The location of a person's new home will be guided in the same way that we all choose where we will live, by taking account of what we want nearby such as access to shops, relevant local services and the availability of a suitable house.

Many of the new homes will be inspected by HIQA and will be subject to the same standards required in the larger settings in relation to care plans, staffing, facilities, safety and community involvement.

Who will support people who move to new homes in the community?



Service providers will ensure people moving to their own home will receive the support they require to be safe and live the life of their choice. The supports to be provided for each person will be agreed before the person moves. Each service provider will engage with the person and their family in relation to the arrangements that will be put in place.

The service provider will continue to regularly review the support arrangements for each person to ensure that they are meeting the person's needs. Some staff from the current residential setting may continue working with people as they move into the community. In some cases there will be new support staff.





In some circumstances, individuals may be supported to access other residential care services once this is in line with their wishes and will meet their needs. This might include alternative models of community living; host family arrangements or accessing generic services such as nursing homes for older people.

People will be supported to link in with their local communities and to explore their own interests and choices. When people move into the community, they will be supported to access community health services where this is appropriate i.e. their own GP, the local pharmacy, public health nurse.

What happens when a person's current need changes?

*"Nothing about us,
without us"*



If a person's needs change or their health deteriorates, the service provider will respond with the appropriate supports in the same way they currently do for people in congregated and community settings.

A decision may be taken in some cases as to whether it is in the best interests of the person to continue supporting them in their current home or to facilitate and support them to move to another setting. This will be done in consultation with the person and their family.

Who should I talk to if I have any other questions and where can I get more information?

If you have any queries specifically regarding your relative, we recommend that in the first instance you contact your current service provider.

For more information about the policy, please visit our webpage www.hse.ie/timetomoveon or you can contact us directly by email at timetomoveon@hse.ie



A video featuring residents who moved from St. Raphael's Centre in Youghal is also available on the Time to Move On webpage. In the video family members speak about the experience from their viewpoint.

There are also videos available on the Genio Trust website www.genio.ie featuring residents, families and staff who have recently been involved in moves from large settings to the community.

