



Time to Move on Newsletter January 2020



Welcome, to the fourth “Time to Move on” Newsletter, aimed at keeping people informed about the progress of the implementation of “Time to Move On from Congregated Settings - A Strategy for Community Inclusion”.

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Staff at the celebration marking the closure of St. Margaret’s



The first mover was, in many ways, the bravest. She was supported around her fears but was clear she was not letting them stop her; she did not want to be left til last so she decided she wanted to be first to walk out the gates to her own home

Quote from the CEO of St. Margaret’s

A new home in Waterford



Did you know our dedicated Time to Move on Webpage is regularly updated?

Our webpage has recently been revamped and now includes sections dedicated to service users and their families; service provider resources and reports and publications.

On an on-going basis new resources, links, video stories and other relevant material are added to the page, so follow the link to see the changes. www.hse.ie/timetomoveon



Transforming Lives

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

Celebrating the Closure of St. Margaret's, Donnybrook

In May 2019, St. Margaret's celebrated the closure of their residential campus with a farewell Mass and Barbeque. This event marked the last day in the chapter of the lives of the 70 women who had lived most or all of their lives in institutions and had been in St Margaret's at the start of the journey that began in 2007.

St. Margaret's celebrated the women's individual journeys as they took their own decisions, made their choices about where and with whom they would live. This was also a journey with families, many of whom had believed that the support and care of a safe place in a group home was the best option

In this extract Breda O'Neill, Chief Executive of St. Margaret's sets out some of that journey,

St. Margaret's in its time was seen as the best option and always considered a good service where people were well cared for.

But nobody saw the individual adult women who had hopes and dreams. Out of conversations started in 2007 about home and "My Own Front Door" we started to listen; to hear the conversations and we started to imagine what it would be like; we imagined on behalf of the women. The initial overwhelming response from staff was that "they" could never do that but the voices of "why not" came through.



Celebrating the closure of St Margaret's

A plan to bring about change was initiated and both the Board and the Religious Sisters of Charity supported the change from the outset. With funding from the existing budget and some financial support from the Religious Sisters of Charity, changes inside St. Margaret's could begin.

Afterwards one family member said "thank you, all my life I have told my sister what to do; now she's living in her own home and she's telling me what to do – thank you for making me listen"

In 2010 St. Margaret's commenced a listening session with the women and their families around their move to their own home. The women were clear on what they wanted. After a life in institutions they wanted their own space, their own place. Building trust around the change took time but families walked the road of change in their support for their loved one.



Celebrating the Closure of St. Margaret's, Donnybrook

When "Time to Move On" was published in 2012, St. Margaret's was on the way towards community inclusion, having reconfigured the service to a social care model and stripping back some of the severely institutional parts of the service.

The first mover was the bravest, greatest woman. admitted she was scared but didn't want to be left 'til last so she wanted to be first to walk out the gates to her own home.

St. Margaret's had to journey with her and this had to be done with care, support, building relationships and trust.

St Margaret's supported people to build their competencies through developing their roles and goals, engaging in their local community, getting involved according to each person's wishes, supporting their independent choices, supporting them to keep home, to be at home, working with each person, one step at a time, one day at a time, journeying with them in their time, in their space, at their pace, as they need.

Not without its challenges St. Margaret's recruiting, engaging and developing staff in a way that supported each person. They built relationships with and engaged with the Local Authorities and Disability Steering Groups to raise awareness of the housing needs of people in institutions was central to supporting people to accessing housing.



Breda O'Neill CEO celebrating with ladies at the closure of St Margarets

For the full story, please see the Time to Move on webpage www.hse.ie/timetomoveon/

St. Margaret's IRL-IASD

St. Margaret's

St. Margaret's Donnybrook has reconfigured into St. Margaret's IRL-IASD Ltd, working with people on an individual basis, according to their need, will and preference; supporting them achieve fully inclusive lives where they assert their **independence, autonomy and self-direction** at home, at the heart of their family, friends and society.



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Making a Home: A practical guide to creating a home and moving to the community



This is a new resource for service providers and other stakeholders who are supporting people with disabilities to move to their own homes in the community. The guide maps the practical steps that might be needed from the time a home is selected through to when the person has moved. The purpose of the guide is to support the process of “making a home” so that the “moving home” process runs as smoothly as possible.

The guide is divided into sections that each focus on specific areas that may need to be considered and there are links provided to the relevant regulations, best practice resources, policies, guidance documents and other useful information and websites.

There are also a number of easy-to-use checklists to track key actions as moves are being planned and undertaken. The guide is available on our webpage www.hse.ie/timetomoveon

Section 1: Housing, Health & Safety	<ul style="list-style-type: none">•Housing & Housing Support•Building Regulations•Fire Safety
Section 2: Home Design and Home Planning	<ul style="list-style-type: none">•Home Design•Fit out, fixtures and fittings•Assistive Technology for the Home•Smart phone, tablet/pc and software apps
Section 3: Supporting the Person	<ul style="list-style-type: none">•Autonomy and Advocacy•Person Centered Planning•Safeguarding and Risk•Activities of Daily Living
Section 4: Legal, Financial and Citizenship	<ul style="list-style-type: none">•Making Decisions and Citizenship•Personal Finances•Residential status of the person in their new home
Section 5: Entitlements, Benefits, Charges and Costs	<ul style="list-style-type: none">•Entitlements and Benefits - Social Protection•Entitlements and Benefits - HSE•Rental / Maintenance Payments
Section 6: Household and Home	<ul style="list-style-type: none">•Planning the move•Running the Household•Financial Running of the Household
Section 7: Administrative Policies	<ul style="list-style-type: none">•HIQA Framework for Designated Centres•Home not a Workplace•Administrative Policies
Section 8:	<ul style="list-style-type: none">•Appendices•Further Resources and Reading•Checklist Toolkit



Thematic Literature Review on meetings the needs of people with significant specialist support needs

A specific literature review has been completed to examine current international policies and the research on evidence-based best practice in meeting the needs of people with disabilities that have significant specialist support needs.



This was undertaken as part of the work of a Time to Move on Review Group who are developing best practice recommendations in this area, to support the implementation of the policy in congregated settings who currently provide care to people with significant specialist needs.

A number of guiding principles emerged from the review as being the consistent features that ensure best practice in the provision of services for people with disabilities and significant support needs.

The review report, which details over 70 resources and includes a full reference list, is available on the webpage www.hse.ie/timetomoveon

In July HIQA (Health & Information Quality Authority) published a review of disability designated centres

5 Years of regulation in designated centres for people with a disability

In this report it was highlighted that,

“Residents loved their new homes and were very happy and content with the staff who supported them. Some residents had transitioned out of larger settings to these community homes and were very happy and positive with their service”

Annual Progress Report 2018

The Annual Progress Report provides validated statistical data about the people that transitioned to new homes in 2018 and their new living arrangements, as well as information and statistics about the population still living in the congregated settings at the end of the year.



A one-page infographic (shown on next page), captures some of the key data and information contained within the report.

The detail in the report demonstrates the number of people moving is only slightly lower than the national targets and there is good compliance with policy in terms of the type of living arrangements people are being supported to move into.

Some statistical information is also provided at Community Health Organisation (CHO) Area level, to support local planning and oversight.

The full report is available on our webpage www.hse.ie/timetomoveon/



Progress made under Time to Move on Policy in 2018



165 people transitioned to the community

94 people passed away

33 people were admitted or re-admitted



Drop in the number of people living in the congregated settings during the year **9%**

For people that transitioned this year:
30 years was spent on average living in a congregated setting
64% had lived in congregated settings for over 20 years

30 people who moved had high medical support needs

52 Years
Average age of people who transitioned to the community



At the end of 2018

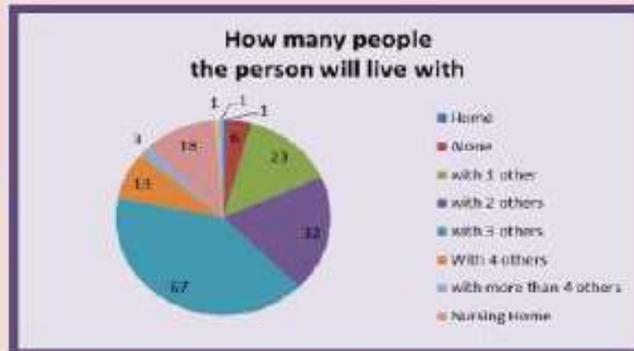
83 Centres

2,136 People in Congregated Settings

15 locations now have less than 10 residents

2 centres closed completely during 2018

6 centres supported more than 12 people to move in the year



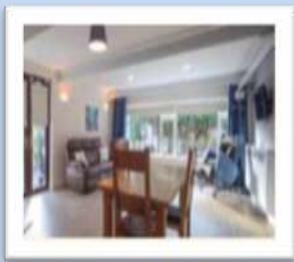
Information extracted from the Time to Move on from Congregated Settings: A Strategy for Community Inclusion Annual Progress Report 2018. The full report is available on www.hse.ie/timelomoveon/



HSE Disability Capital Programme providing homes in the community– Progress So Far



The living and dining room during works in a new home and the completed interior below



Outside a home that was being renovated



A completed kitchen in a renovated home



The HSE are managing the multi-annual funding of €100 million funding allocated to provide new homes for people moving from congregated settings. The HSE are working closely with services to support the delivery of fit-for-purpose homes by way of new builds, purchase and refurbishing of existing buildings.

The HSE Estates team, part of the HSE Health Business Services, who manage the capital budget are working closely with the local services in delivering on the capital programme. Now, at the half way point with €53 million allocated, the positive impact of this programme can be seen.

Disability Capital Programme Time to Move on Policy Implementation €53m allocated 2016 - 2019



Each home is chosen and developed to support the residents to have meaningful choices and control of their lives, to enable them to participate in their chosen community and to ensure that as their needs change they can continue to live well in their own homes, to the greatest extent possible. Taking a person-centred approach to housing is helping to ensure that the new residents in each home are at the centre of the decision making process.

Since this programme started in 2016 there have been dramatic changes in the housing market impacting on both the cost and availability of properties and for contractors to carry out the work needed for renovations and adaptations. This will continue to impact on what can be achieved within the budget and the time that it takes for new homes to be sourced and ready for people. The HSE Team and service providers are aware of these challenges and are working closely to overcome obstacles and capitalise on new opportunities as they arise.



New Housing Circular relating to Capital Assistance Scheme applications

In October the Department of Housing Planning and Local Government issued Housing Circular 32/2019 in relation to Capital Assistance Scheme (CAS) Applications.

This circular introduces new forms for all Capital Assistance Scheme (CAS) Projects and provides additional technical and cost guidance for the provision of housing for people with a disability.



Housing Circular 32/2019 applies to all CAS housing proposals, but there is an emphasis on providing housing for people currently living in congregated settings in order to support the Government's deinstitutionalisation policy.

The circular has been drafted to provide further guidance on issues that have arisen relating to application procedures and selection of Approved Housing Bodies (AHBs) to provide CAS funded housing. The circular provides guidance on the application procedures, the selection of AHB's to provide CAS funded housing and applies to applies to new builds, conversions or acquisitions and gives guidance on scale of provision, new build approaches, adapting existing dwellings, location, value for money and fire safety provisions.

In accordance with Circular 45/2015, AHBs and service providers are required to engage with the Local Authority and the HSE in developing proposals that will support people with disabilities to move out of congregated settings. AHBs and service providers are required to include certification to

this effect when submitting their proposals to the Local Authority (LA).

The circular states that Local Authorities should "proactively liaise with the HSE and AHBs with regard to the provision of accommodation in the community for the people in the institutions" and reaffirms that "CAS funded housing for people with disabilities, including those moving out of congregated settings, should utilise ordinary looking houses in mixed residential neighbourhoods, amongst the rest of the population."

Housing Circular 32/2019 introduces a revised CAS 1 Application Form, which must be submitted by AHBs for all CAS proposals. On the revised CAS 1 Form, **Section 7A must be fully completed by the Approved Housing Body, Service Provider, HSE Disabilities and HSE Estates where housing is being provided for people with disabilities.**

In order to ensure that access to CAS funding for people with disabilities is maximised it will be essential that the relevant HSE Disability Managers and HSE Estates Managers at CHO level engage with the AHB's and service providers in their area around potential CAS applications and ensures they are dealt with in a timely manner.

What is in Housing Circular 32/2019?

- 1. Procedures to be followed by Local Authorities (LAs) when requesting Approved Housing Bodies (AHBs) to submit CAS proposals for People with a Disability*
- 2. Submission of a CAS proposal by an AHB to a LA*
- 3. Scale of Provision*
- 4. New Build Units for People with a Disability*
- 5. Adapting Existing Dwellings for People with a Disability*
- 6. Fit out of CAS units*
- 7. Choice of Location*
- 8. Value for Money*
- 9. Fire Provisions*
- 10. Approval Process*
- 11. AHB regulation and eligibility for CAS funding*
- 12. Revised CAS 1, CAS 2, CAS 2A & CAS 3 Forms for all CAS Proposals*



Moving to the Community – John’s story

John* is a young man who has significant physical disabilities, has epilepsy and is under the care of a palliative team.



John moved into a congregated setting as a child but in March 2018 he moved from the congregated setting to a new purpose built bungalow in his local community, which was adapted to meet his needs. His new home included a profiling bed, oxygen condensers, a tracking hoist system and a wheelchair accessible vehicle was provided for the house to enable the residents to get out and about. John was registered with a GP that was close to his new home and he continued to access the same pharmacy service. Due to the complex medical needs of John and his housemates, they are supported with 24 hour nursing care as well as support from care assistants and student nurses in their home.

In the first 6 months in his new home John’s social life increased to include attending football matches, to cinema and family fun days in local community. He is now able to go home for visits more frequently, his overall health has improved and family visits to the house have increased. John goes to the GP practice as needed and the palliative care team and other disciplines are involved in his care and come to the house to review him.

** name changed*

“Share the Learning” Register of literature and other resources



To ensure that we continue to support the implementation of the Time to Move on policy in line with current international best practice, we access and review material on a wide range of relevant topics and from a variety of sources on an on-going basis. In the past two years we have reviewed over 250 articles, academic papers, websites and other resources that are relevant to the implementation of the policy, but also in many cases these are equally relevant to the wider disability services.



In order to “share the learning” we have developed a register to log all the material and sites that we review. This register is organised by topics and themes. The key topics covered include ageing with a disability, dementia care, palliative care, behaviours that challenge, community inclusion, organisational and staff development, capacity building etc.



This register is available as a resource to service providers and any other interested stakeholders. If you would like a copy of the current up to date register, please email the team on timetomoveon@hse.ie. As the register is in spreadsheet format, we will send the most up to date version and will be able to search, sort or filter the information to locate specific material.

If there is anything you would like to see in our next newsletter, please contact us at timetomoveon@hse.ie



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