Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

Progress Report

On the Implementation of

Time to Move on

From Congregated Settings:

A Strategy for Community Inclusion

Annual Report 2017

TRANSFORMING LIVES

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

Contents

Introduction

This is the third annual progress report on the implementation of the *Time to Move on: A Strategy for Community Inclusion* policy. This report provides an overview of the work being undertaken at a national level to drive the policy implementation and focuses on the challenges and key success factors that are currently arising for all stakeholders. This report also provides data and analysis on the progress that was made in transitioning people from congregated settings to community based homes of their choice during 2017.

In 2017 there was an increase in the number of people that transitioned to new homes in the community compared to the previous year. This was expected, as in many cases the work to support people to move had started in 2016. However, challenges still arose that impacted the rate of progress, resulting in some people not completing their move during the year. These challenges continue to be both disability-sector specific and of a broader nature, such as the supply of housing which is an issue for many citizens in Ireland. Alongside this, throughout 2017 evidence and learning has continued to emerge that clearly shows there are key success factors that can drive the change process and enable successful transitions.

The information gathered during 2017 is again demonstrating that supporting all stakeholders to recognise and embrace a model that enables people with disabilities to live in the community, is bringing about meaningful and sustainable change for those individuals moving from congregated settings. Supporting the many stakeholders to work together to share this vision and strive towards achieving a person-centred model of support that moves away from more traditional models of service remains a key priority. The individual case studies referenced in the report are incredibly powerful, as they show how significant the change can be for the person and their family when they move to the community.

Looking to the future, this report demonstrates that a co-ordination of activity and resources is essential to support and sustain transitions. This must include building the capacity of disability and mainstream services, gaining the support of all stakeholders and securing ongoing multi-annual investment to deliver the programme fully. This will enable service providers to plan and effectively deliver on the policy by supporting residents “one person at a time”, with meaningful person-centred planning that will deliver positive sustainable outcomes for the people with disabilities and their families.

1. Policy Background and National Context

1.1 Time to Move on

In June 2011 the report *Time to Move on from Congregated Settings: A Strategy for Community Inclusion* was published. The report identified that in 2008 approximately 4,000 individuals with disabilities lived in congregated type settings, defined as

"where ten or more people reside in a single living unit or are campus based".

The report found that notwithstanding the commitment and initiative of dedicated staff and management, there were a significant number of people still experiencing institutional living conditions, where they lacked basic privacy and dignity, and lived their lives apart from any community and family. The report recommended a seven year timeframe for the implementation of the policy from 2012 -2019.

The report made 31 recommendations covering a wide range of issues and identifying a diverse group of stakeholders and responsible bodies. Work is on-going to address all the recommendations as part of the overall work plan of the *Time to Move on* subgroup and in collaboration with other stakeholders. The 31 recommendations are listed in Appendix 1 along with the current implementation status of each action.

The *2016 Programme for Partnership Government* made a commitment to a Disability Capital Programme of €100 million over the period 2016-2021, dedicated to the provision of accommodation for those individuals moving from congregated settings to homes in the community. This programme set a target of a one third reduction in the congregated settings population nationally, which equates to 1,819 people remaining in these settings by the year 2021.

1.2 United Nations Convention on the Rights of Persons with Disabilities (2006)

Ireland is a signatory to the UN Convention on the Rights of Persons with Disabilities (UNCRPD). Article 19 of the UNCRPD states that:

"Parties to the Convention recognise the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;

b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;

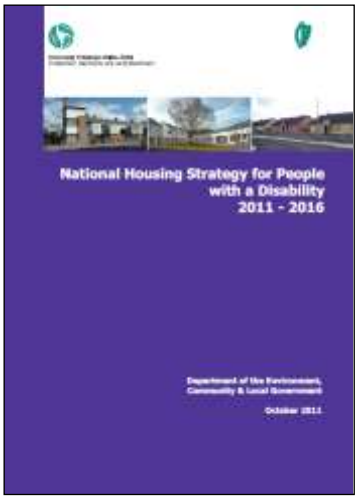
c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs."

The *Time to Move on* policy is fully aligned to the UNCRPD and demonstrates the commitment of Government towards developing and delivering services that will support the right of all persons with disabilities to live in the community as equal citizens.

1.3 Housing Policy

Providing appropriate accommodation to support people with disabilities is fundamental to achieving the implementation of the *Time to Move on* policy. This is supported by housing policy and key strategies introduced by the Government which inform the national approach to the delivery of housing for people with disabilities in the community:

1.3.1 The National Housing Strategy for People with a Disability 2011 – 2016



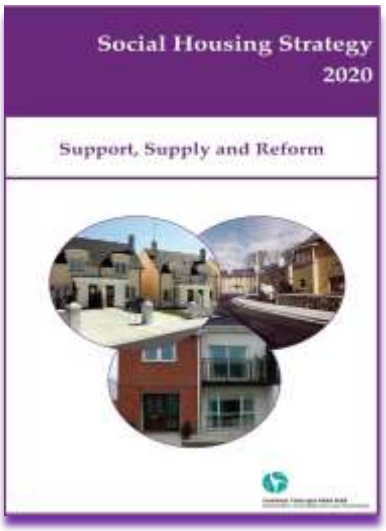
The National Housing Strategy for People with Disabilities (NHSPwD) is a framework for delivering housing to people with disabilities through mainstream housing sources. The vision of the Strategy is:

"*to facilitate access, for people with disabilities, to the appropriate range of housing and related support services, delivered in an integrated and sustained manner, which promotes equality of opportunity, individual choice and independent living*"..

The NHSPwD has been affirmed in *Rebuilding Ireland* (2016) and extended to 2020 to continue to deliver on its aims.

1.3.2 Social Housing Strategy 2020

In 2014 the Department of the Environment, Community and Local Government DHPLG developed and launched the six year *Social Housing Strategy 2020*. The vision of this Strategy is that:



> "*every household will have access to secure, good quality housing suited to their needs at an affordable price in a sustainable community and that the State, for its part, will put in place financially sustainable mechanisms to meet current and future demand for social housing supports…*"

The Strategy sets out to fully meet the Government's obligations to those who need assistance to provide a home for themselves including people with a disability. The *Programme for Partnership Government* contains a commitment to incorporate the needs of people with disability into all future housing policies.

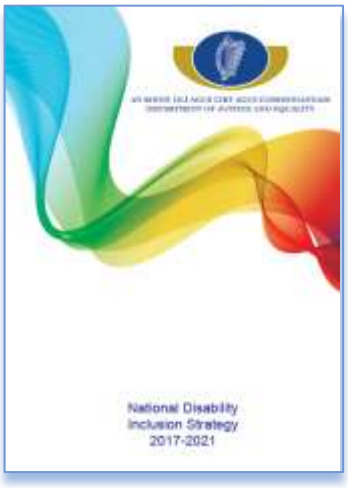
1.3.3 Rebuilding Ireland 2016

In 2016, the Department of Housing, Planning, Community and Local Government (DHPLG) launched its five-year action plan for housing and homelessness in July 2016.

The plan has a number of specific actions relating to housing for people with a disability and extends the NHSPwD to 2020 to continue to deliver on its aims including:

- Increasing the targets for the Housing Adaptation Grant and streamlining the process
- Working with the HSE and Local Authorities on housing issues arising for people who are transitioning from HSE accommodation
- Continuing to support the programme of transitioning people from congregated settings.

1.4 National Disability Inclusion Strategy 2017-2021



The National Disability Inclusion Strategy 2017-2021 was launched by the Department of Justice and Equality in July 2017.

This is a cross-sectoral and cross-departmental strategy that recognises the role of a wide range of stakeholders in bringing about changes that will have a positive impact on the lives of people with disabilities across domains of life that include education, work, home life, community participation and citizenship. The strategy re-affirms the Government's commitment to implementing Time to Move on:

We will continue to implement Time to Move on to give people with disabilities who currently reside in institutions the choice and control over where and with whom they live, within the Community… and to ultimately close all congregated settings …

2. Current Structures Supporting the Implementation of the Policy

There are a number of structures and groups in place to support the implementation of the *Time to Move on* policy. The role and activity of each of these groups is outlined below.

2.1 Time to Move on Subgroup under the Transforming Lives Programme

The *Transforming Lives* Programme is driving the implementation of the recommendations of the Department of Health's 2012 *Value for Money and Policy Review* report and national disability policy to deliver person-centred models of service. The Programme aims to ensure that people with disabilities are supported to make choices about their lives which are available to everyone else in society.

Under the Programme six working groups are in place to examine and progress specific areas of reform. Working Group 2 of the Transforming Lives Programme is concerned with: *Person Centred Model of Service & Support – Implementation, Oversight & Support.* This work includes the implementation of the *Time to Move on* Report for residential services, the *New Directions* report on adult day services and the *National Programme on Progressing Disability Services for Children and Young People (0 to 18 years)*. The remit of the Transforming Lives Programme working groups and subgroups are interconnected and linkages are in place to ensure that the activities and outputs from the groups are co-ordinated.

Subgroup 1 under Working Group 2 is the *Time to Move on* Subgroup with responsibility for:

> *Implementing the initiatives which underpin and enable a new model for residential support in the mainstream community, where people with disabilities are supported to live ordinary lives in ordinary places.*

This is a multi-stakeholder, cross–departmental group that drives the implementation of the policy and provides support and oversight at a national level. For a full list of the 2017 Subgroup members please refer to Appendix 2.

The Time to Move on Subgroup agrees an annual work plan to ensure there is a focus on completing defined deliverable actions. This work plan is aligned with and supports the delivery of targets set out in the HSE National Service Plan and progress is monitored as part of the HSE's overall System Reform Programme.

During 2017 the *Time to Move on* Subgroup continued to work with the Transforming Lives Working Group 1 Subgroup and the National Disability Authority (NDA) on the "Moving In" study. This is a qualitative study using pre and post transition assessments and interviews to assess the impact and outcome for individuals moving to new models of service in the community. The study commenced in 2016 and continued during 2017 with a team of trained interviewers carrying out the assessments with individuals under the direction of the NDA team. A commentary on the findings of the study during 2017 is included in Section 7 of this report.

2.2 National Housing Strategy for People with Disability Subgroup

A multi-stakeholder group was established in 2012 to support the implementation at a local level of the recommendations of the *National Housing Strategy for People with Disability 2011 – 2016 (NHSPwD)*. Led and chaired by the Housing Agency, the Group met regularly in 2017 to progress the strategic aims of the policy, to develop resources that support the delivery of housing for people with disabilities and to support housing authorities and housing providers to develop and deliver plans that will address the demand for appropriate homes for people with disabilities.

The *Third Progress Report on the National Implementation Framework for the National Housing Strategy for People with Disability 2011-2016* which details progress up to the end of 2016 is available on the DHPLG webpage under the Housing section at www.housing.gov.ie/publications/. This report details all the work completed by the Subgroup and makes specific reference to progress in line with *Time to Move on.* The Fourth Progress Report which is due to be published in 2018 will reference the progress of the *Time to Move on* policy implementation during 2017.

2.3 HSE Estates and Disability Team Oversight Group

During 2017 the HSE Estates and Disability Oversight Group continued their work to drive and support the development of appropriate projects under the multi-annual Disability

Capital Programme. This group is made up of key personnel from the HSE Disability Reform Team, HSE Disability Operations Team and the HSE National Estates team. In 2017 the Group were involved in the development of a number of resources and other significant pieces of work which are discussed in more detail under Section 3.3.3.

2.4 HSE Disability Oversight Group

The HSE Disability Oversight Group established in 2016, is made up of staff from the HSE Disability Operational and Reform teams. The group is chaired by the Transforming Lives Programme Manager and brings together staff with expertise in areas including policy, quality improvement and financial feasibility.

Throughout 2017, the group focussed on supporting the Community Health Organisations (CHO's) and service providers to develop and implement project action plans to support the transitions targeted in the National Social Care Operational Plan. They supported the priority sites to develop action plans and funding proposals. Support was also made available to the CHO teams to help ensure that gaps and deficits in the plans could be addressed locally and at an early stage.

Once the project plans were agreed and operational, the focus was on monitoring the milestones and activity set out in the plans, and ensuring that key change processes were being put in place. This oversight enabled the group to focus on supporting the providers around issues as they arose, to identify and support solutions and to gather examples of good practice and shared learning opportunities.

3. Work Undertaken to Drive Policy Implementation During 2017

3.1 "Time to Move on" Implementation Framework

Nine themes are identified as key areas for attention when implementing the *Time to Move on* policy. An Implementation Framework continues to be developed which is comprised of a suite of stand-alone guidance documents referred to as resources. These resources examine specific topics under one of the themes:

- Leadership, Governance, Strategy & Planning
- Communications
- Finance/Resources
- Housing
- Individual planning
- Transition
- HR/ Workforce/Training
- Community Services
- Change Management/Quality Assurance

The Implementation Framework

In Chart 1 below the support structures and resources already in place as part of the Implementation Framework are mapped against the nine key themes. The charts also show the new resources and structures that have been completed in 2017 and those that are currently being developed. These will be outlined in greater detail later in this chapter.

Chart 1: Overview of Implementation Framework Resources

THEME 1: Leadership, Governance, Strategy & Planning

- Revised Project Action Plan documentation suite (PAP) in place
- Monthly monitoring tool introduced for priority sites in 2017
- **Ongoing: Review and Feedback on PAPs and monitoring tool**

THEME 2: Communications

- Revised (2017) Key Messages and Stakeholder Mapping Tool documents in place
- **Ongoing: Continuing development of resources including videos and transition stories**

THEME 3: Finances / Resources

- Key Actions around Finance /Resources identified in Project Action Plan template
- **Ongoing: Funding for priority sites under SRF approved, allocated and under review**

THEME 4: Housing

- Guide to Housing Options for People with Disabilities document in place
- National Housing Strategy Sub Group and HSE Estates & Disability Oversight Group (HEDOG) in place
- Template house and housing specification check list developed by HEDOG in place
- Profile of Housing solutions to support decongregation completed through engagement with each CHO
- **Ongoing: National tracking system in place to capture the risks, issues and solutions arising locally under this theme. Information is periodically shared across the services to promote learning.**
- **Ongoing: Making Homes Workstream to complete work in 2018**
- **Ongoing: Guidance being developed (led by DHPCLG) re funding streams**

THEME 5: Individual Planning

- SSDL Training delivered by Genio as part of SRF projects
- Workshop events held to share learning
- **Ongoing: Further communication planned to share learning**

THEME 6: Transition

- Community Living Transition Planning (CLTP) Toolkit in place
- Pre /Post Transition Assessment Tool developed and roll out commenced
- **Ongoing: SRF Funding to support transfers from 10 priority congregated settings**

THEME 7: Workforce / HR/ Training

- Key Work Streams actions identified in Project Action Plans
- **Ongoing: National tracking system in place to capture the risks, issues and solutions arising locally under this theme. Information is periodically shared across the services to promote learning.**

THEME 8: Community Services

- Key Work Stream actions identified in Project Action Plans
- Review of Local Area Co-ordination Initiatives funded under POBAL completed by DOH
- **Ongoing: Dissemination of positive stories and case studies to demonstrate effective community engagement**

THEME 9: Change Management/ Quality Assurance

- Key Work Stream Task Tracking Plan templates in place . A monthly monitoring tool was introduced in 2017 but due to difficulties in securing the consistent completion of same an alternative direct engagement approach was taken by the Disability Operational team mid year.
- **Ongoing: National tracking system in place to capture the risks, issues and solutions arising locally under this theme. Information is periodically shared across the services to promote learning.**
- **Ongoing: Monthly performance monitoring with support of Oversight group**
- **Ongoing: Review of tracking and data returns that indicate moves completed**

The resources developed as part of the Implementation Framework (Chart 1) are not prescriptive "how to" documents, but aim to guide services towards a best practice approach. Service providers are encouraged to only adopt the elements and approaches that are appropriate to their service taking into account the progress they have made to date and their organisational ethos and configuration.

The on-going development of the Framework is supported and informed by the work of a number of groups and on-going processes including:

- National Housing Strategy for People with Disabilities Steering Subgroup
- HSE & Disability Estates Oversight Group
- HSE Disability Capital Funding Programme
- DHPLG Capital Assistance Scheme
- Service Reform Funded Projects
- Pre & Post Transition Outcome Assessments under the "Moving In" project.

3.2 Dedicated Work streams

During 2017 work was progressed by a number of work streams established under the *Time to Move on* Working Group. Each work stream had specific terms of reference to inform their work and the membership was selected to bring together those with the specialist knowledge to contribute meaningfully to the work. In some cases consultation and discussions with experts outside of the work streams was also undertaken to help inform on best practice. Details of the four work streams are given below.

3.2.1 Work stream 1: Communications

The Communications work stream was set up with the following terms of reference:

> *To examine the key area of communication and engagement as it relates to the implementation of the policy and to develop resources and responses that will enable and support the process.*

The membership of the Group is detailed in Appendix 3.

Progress achieved in 2017:

The communications work stream focussed on driving a positive communication strategy in 2017 that would highlight the gains for people with disabilities, the positive outcomes and the good news stories. This approach was taken intentionally, to avoid the work stream group from focussing on the negative publicity, which would have resulted in the limited resources of the group being used solely to counteract the views of those who are opposed to the policy, without having an opportunity to relay the many positive stories. The work stream supported the development of a number of resources during the year:

- An easy-read version of the *Time to Move on* policy
- Re-vamp of the *Time to Move on from Congregated Settings* webpage, to make it current and more accessible by the public (see below – digital update)
- Development and circulation of video stories and other multi-media resources
- A number of Plain English "*What this means for me?"* information sheets that are tailored for specific audiences

3.2.2 Work stream 2: Review of Community Living Transition Planning (CLTP) Toolkit and policy development

In 2017 it was planned that a small group would review and revise the Community Living Transition Planning toolkit to take full cognisance of the recommendations of the McCoy Report into Aras Attracta. However, as the development of a National Framework for Person Centred Planning is being progressed, it was agreed that this review should be delayed until this Framework is signed off, in order to ensure that these documents are aligned.

The development of this Framework is being led by the New Directions subgroup under the Transforming Lives programme, with the support of the NDA. A draft framework has been developed and during 2017 there was a consultation process with stakeholders. The final Person Centred Planning Framework is expected to be ready for circulation in mid-2018.

Policy Development

In line with the HSE National Framework for the development of Policies, Procedures, Protocols and Guidelines (PPPGS) a subgroup under the Disability Quality Improvement Team was put in place to develop a suite of disability standard policies as required in Schedule 5 of the *Health Act 2007 (Care and Support of Residents in Designated Centres for Persons (Children and Adults) with Disabilities) Regulations 2013 (S.I. No 267 of 2013)*. The *Time to Move on* Project Lead has liaised with the Chair of this subgroup and the

individuals leading the development of specific policies to ensure these documents will be in keeping with the *Time to Move on* policy and will support community living.

PPPG Register

On occasion service providers contact the *Time to Move on* project team to seek guidance in relation to gaps in their current suite of PPPGs that arise when they are supporting individuals to move to the community. During 2017 the gaps were identified in the areas of: administration of medication, personal finance arrangements, financial charges in new homes, staff expenses, socialisation funds.

In order to ensure that transitions are not delayed due to policy and procedural gaps and to support the residential service providers, the *Time to Move on* project team explored the possibility of establishing a central register of the PPPGs already developed by service providers that support community living. It was proposed that the register would enable the project team to support individual providers to link with contacts in other services where a relevant PPPG was in place. A scoping exercise was undertaken which found that the development of a register was not viable, as too few services reverted to contribute.

As an alternative solution, the *Time to Move on* project team continues to support providers on a case by case basis to address any PPPG gaps that arise as individuals are supported to move to the community. Interestingly, the gaps emerging are often quite specific and require a bespoke individual PPPG response. This indicates that the services are developing arrangements that are person centred and often tailored specifically to the residents living in that location, hence the need for bespoke PPPGs.

3.2.3 Work stream 3: Making Homes

The Making Homes work stream is progressing the development of a resource document that will provide information for providers on key focus areas in relation to “Making a Home” for a person with a disability. The document will include information on a variety of areas including: creating homes for behaviours that challenge; balancing the home environment with regulatory requirements; features of low sensory environment; opportunities for and appropriate use of assistive technology etc. This work will be completed in 2018. The membership of the work stream group is detailed in Appendix 3.

3.2.4 Work stream 4: Location Review

The Location Review work stream was set up in 2017 with the following terms of reference (TOR):

1. *To review current residential services in order to determine which locations meet the criteria of a congregated setting and examine how the policy is applicable in each location.*
2. *To identify individuals whose support needs may require specific specialist solution and to identify best practice models for the delivery of safe appropriate and person centred care that can met these support needs.*

Location Register- TOR 1

In order to meet TOR 1, the work stream group is developing a Location Register. Two parallel processes have been underway to progress this: direct engagement with the CHO Areas and a desktop search of data.

Based on the returns from all the CHO Areas and the desktop review, a revised register is being drafted and will be finalised in 2018. A number of locations have been flagged for inclusion/exemption and the process for the review of these settings will be agreed and will commence in 2018.

Specialist Residential Support Needs- TOR 2

A number of actions have been agreed and are being progressed in order to deliver TOR 2:

- Examine current literature and research to identify current models of best practice in relation to residential supports for those with significant support needs
- Gather examples of current good practice within community based residential services in Ireland
- Identify individuals in residential settings whose support needs may require a specialist solution
- Examine application of best practice approaches to meeting residential support needs of individuals identified as requiring specialist supports
- Advise on the appropriate approach to meeting the residential support needs of individuals identified as requiring specialist supports in line with current best practice.

The work stream group has linked with UCD, the IDS TILDA team, TCD and the HRB who are all actively undertaking research that will inform the recommendations in relation to best practice models of support for those with specialist residential support needs.

The group also undertook a number of exploratory desktop searches from which it was evident by late 2017 that there is copious literature available on the specialist support needs of people with disabilities, but that the relevance of this material to the work stream is varied. Furthermore, it is not yet clear that the literature will provide adequate evidence in relation to the models of best practice for individuals across the range of specialist support needs.

In order to address this, a project proposal is being drafted for the development of a resource hub in 2018. The proposal will identify the need for a Research Officer to support providers to access latest literature/research relevant to decongregation and whose initial remit will be gather literature relevant to this work stream. If approved, this would provide an information base to complement the research being undertaken by other agencies and third level educational institutions.

Throughout 2017 members of the work stream group also met with experts working in specialist areas and undertook site visits in order to examine current practice.

The membership of the work stream group is detailed in Appendix 3.

3.3 Other work to drive policy

3.3.1 Digital Update

A video featuring residents, their families and carers from St. Raphael's Centre, Youghal was produced which captures the transition of several people to their new homes in the community and highlights that this kind of move can literally 'transform lives'. The video can be viewed at https://www.hse.ie/eng/services/list/4/disability/congregatedsettings/

This story also featured in the winter edition of the HSE Health Matters, which can be accessed online at the following link: https://www.hse.ie/eng/services/list/4/disability/congregatedsettings/health-matters-december-2017.pdf

With the support of the HSE Digital Team, the HSE's webpage on *Time to Move on* was updated in December 2017. The page now leads with the St. Raphael's video and some positive stories featuring individuals who have moved from congregated settings. Work is on-going to develop more resources for the site including videos and interviews. The site will continue to be developed in 2018 to ensure it is accessible, user friendly and relevant to a wider audience. The page address is www.hse.ie/timetomoveon

3.3.2 Multi-Annual Plan for Housing 2018-2021

During 2017 a comprehensive exercise was completed to determine how the housing requirement for those in congregated settings can be met. Engagement took place with every CHO team to review in detail the plans for each congregated location in their area and agree the CHO priorities, taking cognisance of the finite resources available for the period 2018-2021. Following this process, recommendations for the allocation of the HSE capital funding in the remaining years of the programme 2016-2021 were finalised in late 2017. The indicative multi-annual HSE capital plan was forwarded to the HSE Estates & Disability Oversight Group for their review and consideration. An indicative multi-annual plan has also been drafted that tracks the demand for resources under the other funding streams and housing options such as CAS, social housing , private rental etc. Once approved in 2018, these reports will be forwarded to the relevant stakeholders i.e. HSE Estates, Housing Agency, Department of Health, and DHPLG as this will further inform funding allocations and support the development of realistic activity targets.

3.3.3 HSE Estates and Disability Team Oversight Group (HEDOG)

During 2017, there was a marked increase in the number of HSE capital funded projects being progressed compared to 2016 (see Section 4.1). The HSE Estates and Disability Oversight Group (HEDOG) have taken an active role in monitoring and supporting the progress of all the proposed and approved projects. This involved linking with CHO Estates and operational staff locally and nationally in relation to property selection, project specifications and design issues, project costs, tendering and project timeframes, legal and lease agreements.

Particular attention and progress was made in respect of:

- A template lease agreement for use when properties are purchased by the HSE and leased to the service providers
- The development and dissemination of the Code of Practice for Fire Safety in Community Dwellings
- The development of a template for a community house by HSE Estates, referred to as the “template house”. This template design is for a community house for four individuals with ground floor accommodation, full wheelchair accessibility and a level of specification that provides reasonable “future-proofing” for changing need in relation to bathroom, electrical and mechanical requirements. It is fully costed and

meets all current building and regulatory regulations. The purpose of the template is to inform services and other stakeholders of the specifications to be considered and required within any house project to avoid:

- Expensive post construction adaptations (retro-fitting),
- Delays in securing certification

and to

- Streamline design and project fees by reducing unnecessary duplication of work by consultants and contractors working on individual projects
- Speed up design processes
- Ensure residents needs are met

Houses do not need to follow the exact template and design brief as it is a tool for the purpose of guiding the design process.

- The development of a Housing Specification checklist. This tool was developed by the HSE Estates team under the HEDOG for use by the staff that view and assess potential properties. It aims to streamline the process of property selection by identifying a comprehensive list of features to be reviewed and checked such as drainage, roof construction, fire safety features etc. The tool also supports the teams to accurately estimate project costs, which is a critical factor in determining overall project viability. The tool can support the assessment of properties being viewed for purchase, lease or rental.

3.3.4 Master Data Set validation 2017

The Master Data Set (MDS) is the tool used to collect key information on all those people who are or have been a resident in a congregated setting at any point during the year. Each year the MDS questionnaire is reviewed to ensure the information collected is necessary and relevant. The 2017 MDS was circulated out to capture information on the changes in the circumstances of all those living in congregated settings during 2017 at the year end.

The validation of the Master Data Set (MDS) is a substantial piece of work that is completed with the co-operation of the service providers. When all the returns have been submitted, validated and collated into one data set, the MDS provides robust and detailed information that is used to provide a range of statistical information for the Annual Progress Report. As well as a national overview the information can also be reviewed by CHO Area and by individual agency to help advance the planning process.

Key statistical information from the 2017 MDS is presented later in this report in *Section 5: Population remaining in Congregated Settings* and in *Section 6: Status of Congregated Settings at end of 2017.*

3.3.5 Service Provider Learning Events & Initiatives

During 2017 four events were held that each had a separate and specific focus in order to positively influence, enable and support policy implementation in 2017. Details of the four events are given below. Please note that copies of the presentations delivered are available and can be accessed by sending an email request to timetomoveon@hse.ie

February 2017: Information Day on the Targeted Activity & Project Action Plans for all settings and "New Directions"

An information day was held in Tullamore for local CHO disability teams and service providers, jointly hosted by the Disability National Reform and Operational teams. The purpose of the day was to steer and support the HSE teams and service providers to deliver on the National Service Plan targets. The agenda on the day included:

- An update on the overall Transforming Lives Programme including an update on the status and interconnectivity between the different working groups.
- A presentation on the 2017 Project Action Plan documentation as a project management tool. This documentation enables and supports services in implementing the Time to Move on policy. The pathway for the completion of the project scope statements and the action plans were also outlined.
- A presentation on New Directions which identified the key supports and their relevance in the context of planning for those leaving congregated settings. An overview of the other work of the New Directions programme was also given.

March 2017: HSE Capital Projects Information Day

An information day was held in Portlaoise hosted by the HSE Estates and Disability Oversight group that focussed on supporting the progress of the HSE disability capital projects. The attendees included all the service providers that have been allocated HSE capital and the CHO Area Estates and Social Care teams. The presentations on the day included:

- An overview of the implementation of Time to Move on policy as it relates to housing. This included an overview of funding options and linkage with NHSPwD, Department

of Housing etc. Details of the allocation under HSE Capital Funding were also covered

- Overview of the new Draft Code of Practice for Fire Safety in Community Dwellings
- Details of the "template house" developed by HSE Estates
- Overview of the process for the allocation and approval of capital projects under HSE Disability Capital Programme and role of the HSE Estates Department in the management of HSE Capital funded projects
- Case studies of a number of community houses developed to date.

There was a lively Q & A session at the end of the day that provided an opportunity for those in attendance to raise specific queries in relation to the HSE funded capital projects. The discussions centred on the legal /lease agreements, the adaptation of homes, HIQA designation and revenue funding issues.

April 2017: Facilitated Workshop with congregated settings providers

A workshop was held in Kilkenny, organised and facilitated by the HSE and Genio Trust to enable a diverse group of staff from a small number of providers to come together and discuss and share their experiences of decongregation. There were four locations represented, each of whom brought a team that included front line support workers through to project managers and members of the senior management team. A round table discussion was held in the morning attended by all the participants. In the afternoon the front line staff and managers broke into separate groups which enabled more focused discussions around specific issues relevant to them in their work.

As the four locations were at different stages in implementing the policy, this event enabled those present to share their learning and experience, raise concerns, identify possible solutions and forge collaborative networks going forward. As a follow up to the workshop, all the concerns, issues and solutions discussed that had potential implications for more than one setting were identified and shared through a tracker document. This promotes a collaborative approach and enables on-going sharing.

June 2017: National TTMO Workshop

A learning event was held in Dublin and all congregated settings were invited to send staff actively involved in leading and driving the transition of individuals from congregated to community settings. In total over 65 people attended from the HSE and Voluntary service

providers. The day was divided into a morning information session and an afternoon workshop. The presentations in the morning included:

- An overview of the progress to date under the TTMO policy, Project Lead
- A "Journey So Far" experiences of the transition journey, Brothers of Charity Galway
- Recent experience of closing a congregated setting, HSE Southside Intellectual Disability Services
- An overview of the "Moving In" pre-assessment research to date, NDA.

The afternoon session focussed on reviewing work under the nine key themes in the Implementation Framework and Project Action plan and addressing the queries and issues submitted by participants in advance of the event. Working in smaller groups, participants focused on specific themes and the issues presented. Feedback was taken from each of the groups and discussed by the wider forum at the end of the day.

Following the event all the queries, challenges, issues and solutions that were discussed or documented by the groups under the key themes were compiled into a tracking document and circulated to the participants for feedback. This tracker was subsequently circulated to all the providers for their information.

September 2017: Housing Conference

A presentation was made at the *2017 Biennial National Social Housing Conference on 'Social Housing –The Next Phase Scale | Innovation | New Housing Choice*s' held in Limerick. The presentation on Housing Options for People with Disabilities focussed on the requirements of people transitioning from congregated settings. The conference was attended by staff and voluntary board members of housing associations and co-operatives approved housing bodies (AHBs), local authority officials, elected members, government departments, HSE staff, private sector organisations, financial institutions, tenant bodies and those involved in research. The objective of the conference was to challenge current policies and debate solutions to develop thinking in critical areas of affordability, cost, scale and innovation.

3.3.6 Centre Visits

In 2017, the programme of site visits by the Project Lead, Project Support Officer and other members of the *Time to Move on* Subgroup continued. These visits continued to provide an opportunity to:

- Highlight the work being done at a national level to support the implementation of *Time to Move on from Congregated Settings*
- Improve communication and networking between local service providers and national teams and strengthen the commitment at a local level to implement the policy
- Share learning and target future activity
- Ensure the national team continue to develop their understanding of the configuration of the services that exist within individual organisations and the support needs and circumstances of the residents these providers support.

During 2017, the following centres facilitated members of the Subgroup with on-site visits:

- St. Patrick's Centre, Kilkenny
- HSE, Cluan Fhionnáin, Killarney
- HSE, St. Raphael's Centre, Youghal
- Daughters of Charity, St Vincent's, Lisnagry , Limerick
- Daughters of Charity, St. Joseph's, Clonsilla
- COPE Foundation, Hollyhill and community houses
- Cheeverstown, Dublin
- HSE, Aras Attracta, Mayo
- HSE, Cregg House, Sligo
- HSE, Cloonamahon , Sligo
- Cheshire Ireland, O'Dwyer Home, Mayo
- St. John of God Services, St Raphael's, Celbridge
- St, John of God Services, ,St Marys, Drumcar

In addition to the site visits listed above, meetings were also held with a number of specific project managers and senior management teams to support them in the development of their plans for the implementation of the *Time to Move on* policy.

4. Capital Funding

4.1 HSE Disability Capital Funding Programme in 2017

In 2016 the Department of Health announced dedicated HSE capital funding of €100m over the period 2016–2021 to be targeted to increase the pace of plans for a new model of residential support in the community, in line with the HSE's *Time to Move on* policy.

Following on from the initial allocation of €20 million in 2016, a further tranche of capital funding was allocated towards priority disability projects in 2017. Chart 2 below identifies the 15 centres that were given an indicative allocation of capital funding in 2017.

Chart 2: Centres allocated HSE Capital Funding in 2017

CHO Area	Service Provider
1	HSE, Cloonamahon, Co. Sligo
1	HSE, Cregg House, Co. Sligo
2	HSE, Aras Attracta, Co. Mayo
3	Daughters of Charity, St Vincent's Centre, Lisnagry, Limerick
3	Daughters of Charity, St Anne's Centre, Roscrea
3	Brothers of Charity, Bawnmore, Limerick
4	Brothers of Charity Lota, Cork
4	HSE, Cluan Fhionnáin, Killarney, Co. Kerry
4	Cope Foundation, Cork
4	HSE, St. Raphael's Centre, Youghal, Co. Cork
5	St. Patrick's Centre, Kilkenny
6	Sunbeam Services , Rosanna Gardens
7	St. John of God, St Raphaels Centre, Celbridge, Co. Kildare
8	St. John of God, St Mary's Campus, Drumcar, Co. Louth
8	Muiriosa Foundation, Delvin

Under the HSE Capital programme by the end of 2017 there were 28 projects completed for 101 residents. This includes properties that may have been funded and commenced in 2016. Out of these properties, 16 were opened and occupied by the year end supporting 60 residents to move to their new homes. At the year end the other 12 properties were on schedule to be occupied once the registration and certification by HIQA was in place and the individuals had completed their transition process.

Overall, there are 89 properties either completed or being progressed from the HSE Capital funding across 2016-2017. Collectively these properties will provide a home for 332 residents at an estimated average cost of €132,500 per person. The average cost of the properties is currently working out at €494,000, which includes all fit out and furnishing.

4.2 Capital Assistance Scheme Guidelines (CAS)

In early 2017 the HSE *Time to Move on* Project Lead supported the DHPLG to streamline the CAS application process. The HSE worked closely with the DHPLG prior to the release of Housing Circular 30/2017, known as the "*CAS call for Proposals*". This circular identified the application process for housing projects under the Scheme and confirmed that the Department was accepting applications for capital funding for the delivery, through either construction or acquisition, of housing accommodation, to cater for the priority groups under the Capital Assistance Scheme (CAS) including:

"people with a disability, with a particular emphasis on moving people with disability from a congregated settings into community based living"

A memorandum was issued by the HSE to the disability service providers, both statutory and voluntary, to ensure that these stakeholders were fully briefed on the change in the CAS application process and the implications of this for their services and staff.

By the end of 2017, the demand for CAS funding to support people moving from congregated settings had risen from €2.1 million in 2016 to €3.9 million in 2017.

4.3 Service Reform Fund

The Service Reform Fund (SRF) was established to support the implementation of reform in the Disability and Mental Health Services by providing funding to meet the costs of migrating to a person-centred model of services and supports, in line with government policy. The establishment of the SRF is underpinned by a Memorandum of Understanding between the Department of Health, Atlantic Philanthropies and the HSE. The objectives of the fund focus on:

- Transition to person-centred model of services and support
- Developing capability

- Research and evaluation
- Supporting the development of an advocacy framework

In 2016 work was undertaken to establish the criteria for the allocation of resources to projects aligned to the SRF principles and criteria. Ten sites were prioritised for SRF funding to progress their plans in line with these principles and support these services to achieve an agreed target level of transitions. During 2016 and 2017 there was co-ordinated engagement with the CHOs and providers to review and develop plans and monitor the progress being made against the identified milestones. A group chaired by the Programme Manager for Transforming Lives was put in place to provide oversight, support and feedback. The Group also undertook a number of site visits in 2017. Final funding allocations were made in late 2017 and are subject to a range of conditions and on-going review in order to ensure that progress continues to be made in line with the SRF principles.

5. Population Remaining in Congregated Settings

The HSE National Service Plan (NSP) 2017 identified a target of 223 people to complete their transition from a congregated setting by the end of 2017. In total, the Master Data Set (see Section 3.3.4) confirms that 144 people transitioned during the year, which was 65% of the target. While the NSP target was not met fully during 2017, it should be noted that substantial planning was undertaken during the year and many transitions planned for 2017 are on track to be completed in early 2018. The challenges that arose and impacted on the achievement of the target are explored in more detail in *Section 7 - Analysis of 2017 Activity: Key Success Factors & Challenges.*

By the end of 2017, there were 2,370 people who remained resident in congregated settings. This was a drop of 211 people that takes account of all movements including deaths, emergency admissions and other discharges and transfers, as well as those that transitioned.

Information on the movements in the congregated setting population during 2017 is presented below in Table 1.

Table 1: Movement of people in congregated settings during 2017

Type of movement	Number of People	% of population on 01/01/17
People living in a cong. setting on 01/01/17	2,581*	n/a
A. People who moved to homes in the community in line with the policy	110	4.3%
B. People who transitioned to other appropriate arrangements	34	1.3%
All transitions completed at A & B above	**144**	**5.6%**
People admitted / readmitted in year	36	1.4%
Individuals who passed away in 2017	103	4.0%
People living in a cong. setting on 31/12/17	**2,370**	**91.8%**

* Following a validation exercise the 2016 Annual Report Figure starting figure was increased by 2.

5.1 Transitions in 2017

An analysis has been carried out to look at the profile of the 144 individuals that were supported to transition during 2017 and to examine various aspects of the post transition arrangements, including accommodation type, funding and living arrangements.

Table 2 below identifies the number of people that were supported to move during 2017 by age category. It shows that the most populous age bracket with 54 people (37.5%) was "aged 50 - 59 years". The average age of the individuals that transitioned was 50 years, a slight increase from 2016. The oldest person to move was 84 years old and the youngest person was 18 years of age.

Table 2: Age Profile of residents that transitioned in 2017

Age Category	No. of People	% of those that transitioned
Aged 18 to 29 years	7	4.9
Aged 30 to 39 years	23	16.0
Aged 40 to 49 years	30	20.8
Aged 50 to 59 years	54	37.5
Aged 60 to 69 years	17	11.8
Aged 70 to79 years	9	6.3
Aged 80 plus	2	1.4
Not Known	2	1.4
Total	**144**	**100**

Table 3 identifies the primary disability of the people that were supported to move during 2017. It shows that 66 people who transitioned have a severe intellectual disability, accounting for almost 46% of all those who moved. There were 36 people (25%) with a moderate intellectual disability and a further 30 people (20.8%) with a profound disability who also moved during 2017.

Table 3: Level of Disability of the people that transitioned in 2017		
Primary Disability Identified	**No. of People**	**% of those that transitioned**
Mild I.D.	4	2.8
Moderate I.D.	36	25.0
Severe I.D.	66	45.8
Profound I.D.	30	20.8
Physical & Sensory I.D.	4	2.8
Dual Diagnosis I.D.	4	2.8
Total	**144**	**100**

Table 4 below identifies the level of support needs for all those that transitioned. High levels of support were required by 100 people (69.4%). A further 23 (16%) required moderate levels of support with 14 (9.7%) requiring intensive support. The level of support for those moving to the community has increased year to year, as the proportion of those with high or greater than high support needs is now 79% compared to 62% in 2016.

Table 4: Level of support needs of the people that transitioned in 2017		
Support Needs Identified	**No. of People**	**% of those that transitioned**
Minimum	2	2.8
Low	4	1.4
Moderate	23	16.0
High	100	69.4
Intensive	14	9.7
Not identified	1	0.7
Total	**144**	**100**

Looking at the *Level of Disability* (Table 3) and the *Level of Support Needs* (Table 4) together, of the 66 people with a severe level of disability who transitioned 59 (almost

90%) required high levels of support and 5 people required intensive support. For people with a profound intellectual disability, 28 individuals (over 90%) required high levels of support and 2 people required intensive support.

In addition to identifying the level of support needs service providers also indicated that 63 of the 144 residents who transitioned required support for behaviours that challenge. Of these 63 residents, 9 required intensive support, 51 required high levels of support and 3 required moderate levels of support.

Table 5 below identifies the length of time individuals had lived within a congregated setting prior to their transition in 2017. The longest period lived in a congregated setting was 65 years, while the shortest time recorded was less than a year. There were 11 people (7.6%) of those that moved in 2017, who had lived in congregated settings for over 50 years before they transitioned.

Table 5: Length of stay in a congregated setting prior to transition

Length of Stay as at 1/1/2017	No. of People	% of those that transitioned
Less than a year	1	0.7
1 - 4 years	3	2.1
5 -10 years	7	4.9
11 - 20 years	22	15.3
21 - 30 years	29	20.1
31 - 40 years	40	27.8
41 - 50 years	28	19.4
Over 50 years	11	7.6
Not specified	3	2.1
Total	**144**	**100**

The following information is given by CHO Area in Appendix 4:

- Age profile of residents that transitioned in 2017
- Level of disability of the people that transitioned in 2017
- Level of support needs of the people that transitioned in 2017
- Length of stay in congregated setting prior to transition

Table 6 below identifies the housing solution used to support the people that transitioned during 2017. The most frequently identified housing solution to support people that transitioned was through placements in new community houses as was the case in 2016. 88 people (61.1%) moved to new homes in 2017, a significant increase year on year as 26 people (35%) moved in 2016 to new homes. A further 21 people (14.6%) moved to existing community houses and 19 people (13.2%) moved through voluntary housing associations.

Table 6: Housing solution for those that completed transition process		
Type of Housing Arrangement	**No. of People**	**% of those that transitioned**
Living Arrangements in line with policy		
Private Rental without Rent Supplement	2	1.4
Nursing Home	11	7.6
Through Voluntary Housing Body	19	13.2
New Community Home	88	61.1
Social Leasing (RAS)	1	0.7
Social Leasing (Leased)	0	0
Private Rental with Rent Supplement	0	0
Existing Community House	21	14.6
Family Home	1	0.7
Other & Not Specified	1	0.7
Total	**144**	**100**

The choice of housing available to support those planning to transition is being impacted by limited access to suitable mainstream social housing options, the competitive housing market for rental and purchases and the lack of security in the private rental markets.

The new living arrangements in place for the people that transitioned during 2017, are outlined in greater detail in Tables 7 and 8, noting that some transitions are to appropriate alternative solutions, albeit not strictly in line with the recommendation that people do not live with more than three other people with a disability.

Table 7: Transition arrangements where there are no more than 3 other people with a disability		
Type of Living Arrangement	**No. of People**	**% of those that transitioned**
Living Arrangements in line with policy		
Person is living alone	11	7.6
Sharing with one other person	8	5.6
Sharing with two other people	18	12.5
Sharing with three other people	72	50.0
Family	1	0.7
Subtotal	**110**	**76.4**

Table 7 shows that of the 144 people that transitioned, 110 people (76.4%) of those that moved out now live in arrangements with up to three other people with a disability or sharing with family members. This is an increase of 10% on the 2016 figures, where 66% of transitions were in line with policy.

In 2017, 72 people (50.0%) moved to supported arrangements where they are now sharing with three others, 18 people (12.5%) are living with two other people, 8 people (5.6%) are sharing with one other and 11 people (7.6%) are living alone.

Table 8 shows the living arrangements for the other 34 individuals who transitioned to a range of alternative accommodation appropriate to their needs.

Table 8: Transitions to other appropriate alternative arrangements		
Type of Living Arrangement	**No. of People**	**% of those that transitioned**
Other Living Arrangements		
Existing Group Home with up to 8 others	4	2.8
New Group Home with more than 3 others	18	12.5
Other - Palliative Care	1	7.6
Other - Nursing Home	11	0.7
Total	**34**	**23.6**

These are transitions where residents were supported to move in line with their person-centred plan to other arrangements that offer an appropriate model of accommodation and support. This includes 18 people (12.5%) who moved to new or existing community group homes that fall outside the congregated settings policy as the houses have less than 10 residents but do have more than 4 residents as set down for new residential services.

There were also 11 people that transferred to mainstream nursing homes, reflecting that as people with a disability get older, in some cases meeting their age-related needs can become the priority. Eight of the people who moved to nursing homes were aged over 60, with 4 having a moderate level of disability. One person was aged 42 and two people were in their fifties. One person moved to a palliative care setting during 2017.

Table 9 below examines the financial implications of the new arrangements supporting people that transitioned in 2017. In 19 cases people were supported to transition on a cost neutral basis, but service providers also confirmed that for 51 transitions there was a cost implication. Unfortunately, service providers did not provide this information in 74 cases (51.4%), which is a significant data gap in relation to cost implications.

Table 9: Financial Implications of new arrangements completed in 2017

Financial Impact	No. of People	% of those that transitioned
Achieved on a cost neutral basis	19	13.2
Recorded a cost implication	51	35.4
Not stated	74	51.4
Total	**144**	**100**

Table 10 identifies the range of financial sources that were used to support the people that transitioned in 2017. Based on the information received where transitions were not cost neutral, funding was provided by the HSE in 19 cases and in 8 cases by the service providers. Almost 50% did not advise of funding source.

Table 10: Funding sources used where transitions were not cost neutral		
Financial Impact	**No. of People**	**% of those that transitioned**
HSE	23	16.0
Service provider	8	5.6
Not stated	20	13.9
Total	**51**	**35.5**

Table 11 below examines the most significant challenges identified by providers in relation to supporting the transitions completed in 2017. Similar to previous years, in the majority of cases (56.9%) no specific challenges were identified, which may indicate that no difficulties were encountered or it may only reflect that information was not provided on this query.

Table 11: Primary challenge Identified in process for those that completed transition		
Primary Challenge Identified	**No. of People**	**% of those that transitioned**
HIQA Registration issues	6	4.2
Funding Issues	29	20.2
Non Availability of Suitable Accommodation	17	11.8
Adaptations/Time lag property purchase	10	6.9
None specified/other (2)	82	56.9
Total	**144**	**100**

However, amongst those where a challenge was identified, funding issues was the most prevalent, noted as impacting on 29 (20.2%) transitions. The non-availability of suitable accommodation was an issue in 17 cases (11.8%) which was an increase on the 6 (8.21%) cases identified during 2016. In 6 cases (4.2%) HIQA registration was identified as an issue. It was notable that “stakeholder objection” was not identified as the primary

challenge for any transition completed in 2017. It is expected that this is due to a combination of factors including that services intentionally worked with individuals that wished to move, staff and families that supported the moves as well as carefully managing the engagement and communication with all stakeholders throughout the process.

5.2 Individuals who passed away during 2017

During the year, 103 people living in the congregated settings passed away. Table 12 below identifies the degree of disability, age profile and level of support needs of the people who passed away.

Table 12: Profile of People living in congregated settings who passed away in 2017

Degree of Disability	Total	%	Age	Total	%	Support	Total	%
Borderline	0	0.0	0-18	1	1.0	Low	1	1.0
Mild	4	3.9	18-29	2	1.9	Minimum	0	0.0
Moderate	34	33.0	30-39	3	2.9	Moderate	10	9.7
Severe	42	40.8	40-49	16	15.5	High	78	75.7
Profound	11	10.7	50-59	26	25.2	Intensive	9	8.7
Phys. & Sensory	4	3.9	60-69	18	17.5	Not stated	5	4.9
Dual Diagnosis	2	1.9	70-79	21	20.4			
Not Specified	6	5.8	80 Plus	13	12.6			
			Not stated	3	2.9			
	103	**100.0**		**103**	**100.0**		**103**	**100.0**

Analysis of the data shows that over 75% of the people who passed away required high levels of support. 40.8% (42 people had a severe intellectual disability and a review of the age profile of those who passed away, shows that the over 50% (52) of the people who passed away were 60 years of age or over.

By cross-referencing the information provided, it is confirmed that 10 people (10% of those who passed way) were admitted during the period 2015 - 2017. Two people admitted during 2017, four people admitted during 2016 and four people admitted during 2015.

5.3 Admissions during 2017

Overall there was a drop of 211 in the number of people still living in congregated settings by the end of the year. However, as in previous years, there continues to be a small number of admissions. During 2017, 36 individuals were recorded as new or return admissions to congregated settings during the year.

An analysis of the profile of the individuals admitted in 2017 was undertaken. Table 13 examines the age profile of the people admitted. This shows that 9 people (25%) admitted were aged between 40 and 49 years of age and a further 9 (25%) people admitted were aged between 50 and 59.

Table 13: Age Profile of residents admitted in 2017

Age Category	No. of People	% of those Admitted
Aged 18 to 29 years	4	11.1
Aged 30 to 39 years	5	13.9
Aged 40 to 49 years	9	25.0
Aged 50 to 59 years	9	25.0
Aged 60 to 69 years	7	19.4
Aged 70 to 79 years	1	2.8
Aged over 80 years	1	2.8
Total	**36**	**100**

Table 14 below identifies the level of disability of the people that were admitted during in 2017.

Table 14: Level of disability of the people admitted in 2017

Primary Disability	No. of People	% of those admitted
Mild	3	8.3
Moderate	18	50.0
Severe	10	27.8
Profound	0	0.0
Physical & Sensory	4	11.1
Not specified	1	2.8
Total	**36**	**100**

This confirms that 18 people (48.6%) who were admitted have a moderate degree of disability and 10 people (27.0%) have a severe level of disability. The data indicates that almost 62% of those admitted (22 people) required a high level of support with three people requiring an intensive level of support.

The reason given for admission is captured in Table 15 below. A large percentage of the people admitted (16 of 36), were already receiving a residential support from the service providers, either living within community based residential services or in a long term respite placement.

Table 15: Reason for admission of individuals in 2017

Reason Identified	No. of People	% of those admitted
From community service due to changing need	14	38.9
Conversion of ongoing long-term respite place	2	5.6
Personal Health / Medical Reasons	7	19.4
From home due to change in carer circumstances	7	19.4
Not specified	6	16.7
Total	**36**	**100.0**

Table 16 below identifies the type of settings to which people were admitted during in 2017. This demonstrates that in order to provide support, the use of large campus settings is still an option being used, in some instances.

Table 16: Type of placement to which individuals were admitted in 2017

Type of Placement	No. of People	% of those admitted
Large campus	21	58.3
Part of a cluster on Campus Site	11	30.6
Large Community House	4	11.1
Total	**36**	**100.0**

Whilst there is no specific data available through the master data set to identify the rationale for this, it is reasonable to deduce that these admissions are made as there are available registered residential beds and adequate staff in place within these settings to meet support needs of those being admitted. However, it must be acknowledged that year on year there is an unmet demand for residential places which results in emergency situations arising. Annually up to 400 urgent or emergency residential placements are needed and most of these are met in community settings. Securing placements within the community that can appropriately address support needs and prevent admissions can be challenging and dependent on resource and capacity issues. On this basis, it has not always been possible to address these issues and avoid admission to the congregated setting.

Finally, it can be noted that the rate of admission has remained relatively static with 36 admissions during 2017 compared to 34 in 2016 and 41 during 2015. In general admissions each year account for 1-2% of all those in a congregated setting.

Additional data is gathered from time to time to review the long term arrangements that arise for those admitted. Recent data demonstrates that these admissions are either short term arrangements put in place to provide specialist end-of-life care or placements to support individuals and their families through a particular crisis or change in needs. In the latter case, service providers plan carefully to support the person to move back to the community at the earliest opportunity.

6. Status of Congregated Settings at end of 2017

At the 31st December 2017 there were 2,370 people who remain living in congregated settings, captured on the master data set. Since the *Time to Move on* report was published and tracking commenced in 2012, there have been changes in the overall landscape of the congregated settings. Below is an analysis of the profile of the population remaining in congregated settings at the end of 2017 and the type of services that remain.

6.1 Profile of Residents in congregated settings on 31/12/2017

Table 16 below summarises the age profile of the residents that remained in congregated settings at the end of 2017. There has been a shift in the age profile of the population remaining in congregated settings since the *Time to Move on* Report was published in 2011. The original report found that half of all residents were in the age range 40-60 years, with a further 20% aged over 60. The 2017 data confirms, similar to the last two annual reports that the population in the congregated settings is ageing. Year on year the proportion of residents in age ranges over 50 years, has increased from 57.9% in 2016 to 60.4% in 2017.

Table 16: Age profile of residents remaining in congregated setting at end of 2017

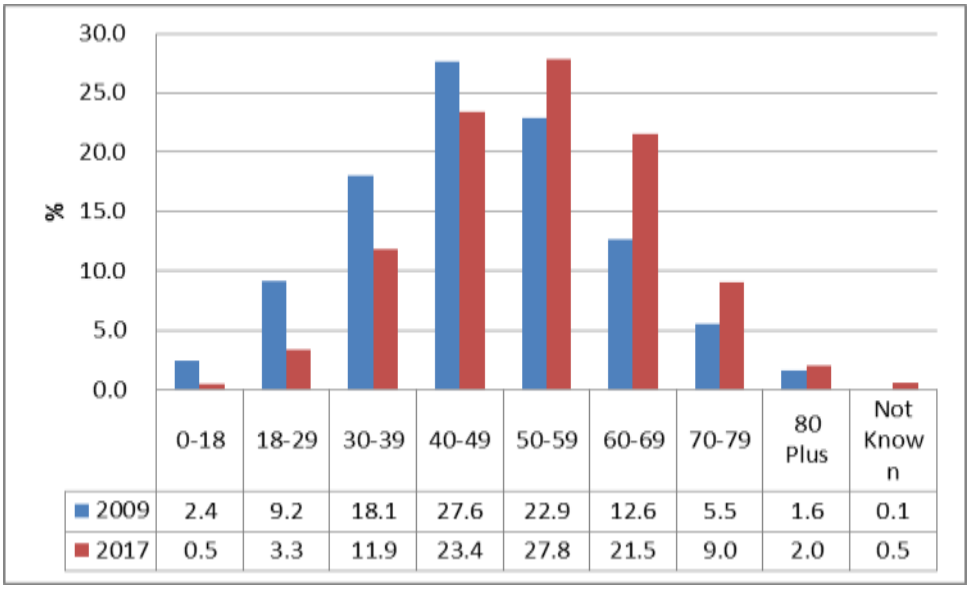
Age Category	No. of People	% of People
under 18	11	0.5
18-29 years of age	79	3.3
30-39 years of age	281	11.9
40-49 years of age	555	23.4
50-59 years of age	659	27.8
60-69 years of age	510	21.5
70-79 years of age	214	9.0
Over 80 years of age	48	2.0
No age given	13	0.5
Total	**2370**	**100**

More detailed analysis confirms that over 60% (1,431) of the resident population is now 50 years of age or older. Similarly the population under 50 has decreased from 41.4% in 2016 to 39.1% in 2017. There are now 11% of the residents aged over 70 years of age, which is 214 people and a further 48 people are now aged 80 or older. The data is reflecting that similar to people with disabilities in the community, those in congregated settings are living longer.

Chart 3 below captures the age profile of the population in 2009 and again in 2017. Showing the "decade age ranges" this demonstrates the shift in the age profile of the residents. In 2009 the most populated age category was the 40 to 49 years with 27.6%. In 2017 the largest group fall into the 50-59 age bracket with 659 residents or 27.8% of the population in congregated settings in this age bracket.

The biggest percentage increase is in the 60-69 age grouping which has increased from 12.6% to 21.5% of the total number of people remaining in a congregated setting. The overall percentage of people over the age of 70 has increased from 7.1% of the population to 11%. This confirms that the resident population is ageing, which will bring additional challenges as outlined elsewhere in this report.

Chart 3: Age profile of residents 2009 & 2017



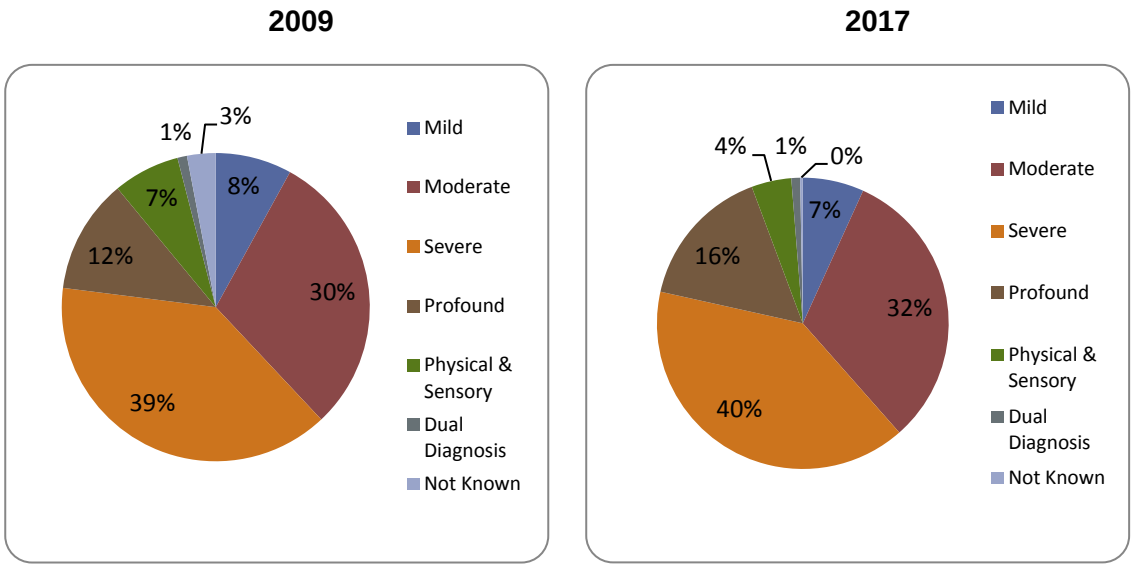
	0-18	18-29	30-39	40-49	50-59	60-69	70-79	80 Plus	Not Known
2009	2.4	9.2	18.1	27.6	22.9	12.6	5.5	1.6	0.1
2017	0.5	3.3	11.9	23.4	27.8	21.5	9.0	2.0	0.5

Table 17 summarises the level of disability of the residents that remained in congregated settings at the end of 2017. The data reflects that the population currently living in congregated settings continue to have high levels of disability with over 1,323 (56%) identified as having a severe or profound level of disability.

Table 17: Level of disability of people in congregated settings at end of 2017		
Primary Disability Identified	**No. of People**	**% of Residents**
ID/ MH	23	1.0
Borderline	3	0.1
Mild	158	6.7
Moderate	751	31.7
Severe	948	40.0
Profound	375	15.8
Physical & Sensory	105	4.4
Not specified	7	0.3
Total	**2370**	**100**

A comparison of the level of disability of residents in 2009 and 2017 is given in Chart 4 below. The percentage of people with a severe intellectual disability has remained steady at between 39-40% but the overall number has reduced by 36% from 1,536 to 948. There has been a 4% rise in the percentage of residents that have a profound level of disability from 12% in 2009 to 15.8% in 2017. Overall, even though the percentage of residents with a severe or profound disability has risen by 5% from 51% to 56% of the total, the actual number of people with this level of disability has fallen to 1,323 compared to 2,164 in 2009.

Chart 4: Level of disability of residents



As previously outlined in Section 5.1 (Table 3), 96 people who transitioned in 2017 had a severe or profound intellectual disability, which was 66% of all those who moved.

In relation to people with a mild disability, there is a slight reduction from 8% to 6.7% of people remaining in a congregated setting, but the overall numbers have actually fallen by 53% from 337 in 2009 to 158 in 2017. The number of people whose primary disability is a physical and sensory disability continues to decrease. In 2009 there were 297 people identified as having primary physical and sensory disability, which accounted for 7% of the congregated setting population. In 2017 this has fallen to 105 people or 4.4% of the congregated settings population.

In addition to the primary disability, Table 18 outlines the level of support required by people remaining in congregated settings at the end of 2017. Almost 68% (1,610 people) require a high level of support with just under 7% (159 people) requiring intensive support.

Table 18: Level of support required by people in congregated settings at end of 2017

Primary Disability Identified	No. of People	% of Residents
Low	144	6.1
Minimum	15	0.6
Moderate	437	18.4
High	1610	67.9
Intensive	159	6.7
Not specified	5	0.2
Total	**2370**	**100**

Of those identified as having high support needs there are 780 people (48.4%) who have a severe intellectual disability and 351 people (21.8%) have a profound intellectual disability. A further analysis and cross reference of information on those requiring a high level shows that 652 of these individuals are aged 50 or under (40.5%), 466 (28.9%) are aged between 50-59 with 485 individuals (30.1%) aged 60 or over. This is an important observation, when we note that the life expectancy for people with disabilities, whilst below that of the general population, has also increased.

It is unclear from the data whether it is the case that the people with higher supports are now

living longer or that increased needs are arising as the population gets older. It is likely to be a combination of both these factors, which will both have long-term resource implications.

The 2017 master data set also provides scope for details to be provided on additional specific needs that might impact an individual's residential supports. There are a wide range of specific conditions identified, that fall under the heading of medical conditions, genetic conditions, acquired disabilities, epilepsy, high nursing, complex care needs, autism, physical disabilities and mental health conditions. Please note that these categories are not necessarily mutually exclusive.

Table 19 examines the prevalence rates of high medical needs/ medical frailty and behaviours that challenge, as these two categories were captured in the original report. The data shows that whilst the overall number of people presenting with these additional needs has dropped by 40-60% the rate of occurrence amongst the congregated setting population has marginally increased by 0.7-3.7%.

Table 19: Prevalence rates of high medical needs and behaviours that challenge

Length of Stay as at 31/12/2017	No. of People	% of Residents
2009		
High Medical Needs /Medical Frailty*	723	17.6%
Behaviours that challenge	1089	26.6%
2017		
High Medical Needs /Medical Frailty*	433	18.3%
Behaviours that challenge*	719	30.3%

**The 2009 figures were based on a survey completed by service providers. The 2017 figures are based on the master data set question where high medical needs were identified.*

Finally, an analysis was done to look at the time the individuals have spent living in congregated settings. This information is provided in Table 20 below which shows that over 53.8% of individuals have now been living in a congregated environment for over 20 years (not including those for whom no information is available).

The number of people who have lived in a congregated setting for less than 1 year is 32 (1.4% of the overall population) which is lower than the number of people admitted. The

number of people resident between 1-10 years is 10% of the total.

Looking at this data for the length of time people remain in the congregated settings indicates there is an on-going effort by providers to develop “exit strategies” for those admitted. The impact of this is that the number of people year on year that have remained living in the congregated setting is lower than the rate of admission. A small number of residents are admitted for end-of-life care and pass away in the congregated settings, but there is also evidence that residents admitted for other reasons, such as crisis illness of the primary carer and subsequently supported to move back into the community. This shows that providers recognise the importance of re-integrating people into their communities as soon as possible, before individuals lose their life skills and independence or their connectivity with their local community and network of friends and families.

Table 20: Length of stay in a congregated setting

Length of Stay as at 31/12/2017	No. of People	% of Residents
Admitted during 2017	32	1.4
1 to 4 yrs	115	4.9
5 to10 yrs	120	5.1
11 to 20 yrs	361	15.2
21 to 30 yrs	340	14.3
31 to 40 yrs	305	12.9
41 to 50 yrs	350	14.8
51+ yrs	280	11.8
Not stated	467	19.7
Total	**2370**	**100**

A set of tables are included in Appendix 5 that provide the following information by CHO area:

- Age profile of residents remaining in congregated settings
- Level of disability of the people that remaining in congregated settings
- Level of support needs of the people that remaining in congregated settings
- Length of stay in congregated setting

6.2 Profile of Congregated Setting Locations at Year End 2017

At the end of 2017 there were 21 service providers, returning information on 58 services that collectively are made up of 312 separate units. These units range in size from one person arrangements annexed alongside other larger units or standing alone on a campus, through to centres that have over 20 people living together. Whilst many individuals now have their own bedrooms, there are still a significant number of people that share a bedroom and bathroom facilities. There are also a small number of dormitory-style units still open that provide very little privacy or personal space for individuals

For your information, a map is included on the next page, outlining the geographical spread of the congregated across the nine HSE CHO Areas. This also includes data on the number of congregated centres operated by the HSE and voluntary sector providers in each Area, along with the overall number of residents within these locations. A full breakdown of the services and the range of units, by service provider and CHO Area is provided in Appendix 6.

During 2017, only one congregated setting location was completed closed. This was a large single centre service operated by Cheshire Ireland in Monkstown, Dublin. Details of how this closure was achieved are given in Appendix 7.

Whilst no other locations have closed entirely, a significant number of people were supported to transition from a number of large campus's including 31 people who moved from St. Patrick's Centre in Kilkenny , 16 people who moved from St John of God, St Mary's Centre, Drumcar and 16 people who moved from the St. Raphael's Centre, Youghal. These transitions resulted in some individual units on the campus's being closed and in the re-organisation of the campus accommodation for those remaining to improve their living environment.

Overall, the incremental fall in the number of residents living in the congregated settings, year on year, such as the reduction of 136 in 2016 and 211 in 2017, means that service providers are able to reduce the number of residents living together in particular units and to support internal transfers. This has created the opportunity for some people to live in smaller groups or with others of their choice whilst still in the congregated setting. This can be a valuable first step towards a transition off-campus as it can improve the quality of life of services for individuals, improve opportunities for friendships and activities and enables providers to deliver more person-centred care aligned to individual interests and

Map of Congregated Settings by CHO Area at year end 2017

CHO 1

Service Provider	Nos.	Clients
HSE	6	167
Vol Sector	2	20
Total	**8**	**187**

CHO 2

Service Provider	Nos.	Clients
HSE	1	74
Vol Sector	3	38
Total	**4**	**112**

CHO 3

Service Provider	Nos.	Clients
HSE	-	-
Vol Sector	4	226
Total	**4**	**226**

CHO 4

Service Provider	Nos.	Clients
HSE	2	69
Vol Sector	7	554
Total	**9**	**623**

CHO 5

Service Provider	No	Clients
HSE	1	32
Vol Sector	4	105
Total	**5**	**137**

CHO 6

Service Provider	No.	Clients
HSE	2	32
Vol Sector	8	87
Total	**10**	**119**

CHO 7

Service Provider	No.	Clients
HSE	-	-
Vol Sector	5	416
Total	**5**	**416**

CHO 8

Service Provider	No.	Clients
HSE	-	-
Vol Sector	3	104
Total	**3**	**104**

CHO 9

Service Provider	No.	Clients
HSE	2	149
Vol Sector	7	297
Total	**9**	**446**

support needs.

Year on year there is an increase in the number of locations whose resident population falls below the threshold of 10 residents, which is the definition of a congregated setting. Importantly, these centres continue to be identified as congregated settings on the basis that the service continues to be located in the original inappropriate setting and the service model does not support community living and inclusion.

Irrefutable evidence has to be provided to demonstrate that where a service remains in the original location it can be deemed exempt under the policy on the basis that it has been re-configured to effectively support the residents to live in the community and is in line with the person centred plan.

Table 23: Congregated settings with less than 10 residents at the end of 2017

Name of Setting	Number of Residents
HSE Donegal, Séan O' Heihir, Stranorlar	5
HSE Donegal, Cill Aoibhinn, Donegal Town	8
Cheshire Ireland, O'Dwyer Home, Mayo	6
Cheshire Ireland, Tullow, Carlow	7
St John of Gods, Carmona, Bray	9
Cheshire Ireland, Abbeyview, Sligo,	9
Sunbeam Services, Dunavon, Rathdrum	8
Sunbeam Services, Hall Lodge, Arklow	2
Muiriosa Foundation, St Marys Centre, Devlin	3
Daughters of Charity, St. Rosalie's, Portmarnock	8

7. Analysis of 2017 Activity: Outcomes, Key Success Factors & Challenges

Throughout 2017 there continued to be a focus on supporting individuals to move to new homes in the community from the priority congregated sites. Concurrent to this, the NDA "Moving In" study has been underway to gather qualitative information on the impact of change on those moving to the community, both from the priority and non-priority sites.

7.1 Outcomes

The update and commentary from the "Moving In" study provides a person-focussed qualitative overview of the impact of the policy. This preliminary update captures the learning from the pre and post assessments conducted across the services including both the priority and a number of non-priority locations. The full update is included in Appendix 7, but some of the highlights include:

OUTCOMES

The Transition

- Challenging behaviours have reduced with a resultant reduction in medication for some participants.
- Staff noted the ease of the transition process.
- Residents have settled in their new home quickly
- Positive changes in behaviour have exceeded all expectations.
- Evidence of significant and at times transformative changes in quality of life following the move to the community.

New Homes

- People now live in homes which are quieter, calmer and safer than before.
- Residents now enjoy privacy - a space of their own where they can rest, display family photographs and other personal mementos.

Family

- Family contact is being promoted and increased family contact can develop.
- Families find it easier to visit ordinary homes

Community

- Community integration has greatly increased
- People have more opportunities to engage in physical exercise and activities appropriate to their ability, which is improving overall health and wellbeing.
- The move to the community has promoted social integration as residents now access community based services and activities to a far greater extent.

7.2 Key Success Factors & Challenges

Some centres have been deemed a priority area of concern as they have significant non-compliance issues in relation to meeting the National Standards for Residential Services as regulated by HIQA. Of the 144 people that completed their transition during the year, 119 were from these priority sites.

In 2017, there was evidence of a "sea change" in a number of priority sites, which resulted in the acceleration of the number of people transitioning towards the end of 2017. Reviewing the journey and the progress of these services across 2016 and 2017 demonstrates that there are common key success factors and activities that are creating solutions and driving this. Not surprisingly, the solutions emerging directly mirror some of the challenges that have been highlighted in earlier progress reports, many of which are still noted in Section 7.3 below as they continue to impact the progress of targeted transitions during 2017.

7.3 Success Factors

Notwithstanding the resource issues that can arise in relation to supporting individuals to transition, three success factors have been identified repeatedly as being key components that drive progress. These are:

- Clear, supportive and driven leadership
- Supporting local decision making and local responses
- Prioritising and supporting meaningful engagement and communication.

Under each of the headings of Leadership, Keep it Local and Communication, there are a range of actions and approaches that services have identified as being fundamental to enabling them to make progress in 2017 as follows:

KEY SUCCESS FACTORS

Leadership

- Promoting a Shared Vision from the top down
- Ensuring protected time for leadership/implementation
- Establishing a Project Management Team
- Fostering a culture of Person Centred Planning and Positive Risk management
- Ensuring the development of Clinical governance /Appropriate policies, procedures, protocols, guidelines including
    - Medication management
    - Safeguarding Policies
- Workforce planning
    - Review of rosters to support / implement new ways of working
    - Establishing appropriate reporting relationships
    - Training needs analysis
    - Up skilling /training / Supporting Staff development to transition to new ways of working
- Reviewing existing day programmes

Keep it Local

- Find and enable local solutions, staff on ground best placed to support solutions
- Ensure person centred planning is built into decision making at every level
- Managing transition lead in
    - On-going skill building for residents pre and post transition
    - Managing expectations re staffing
- Community Mapping to support transitions
- Developing Support networks
- Access to community services – GP/Therapies/ Dietetics
- Transport
- Access to day programmes
- Developing links with Local Government / HSE Estates/ Estate Agents / Housing Associations

Communication

- Has to be actively managed and will be on-going communications with all stakeholders at all stages
- Various methods of communication must be explored for the various stakeholder groups
- Continuous communication with the Resident and Family will be required at every stage of the process
- Importance of the Discovery Process
- Access to Advocacy

7.4 Challenges

As can be expected with a significant change programme of this nature, challenges continue to arise that impact on the progress being made. The challenges experienced by services in 2017 fell broadly under the headings of Accommodation, Communication and Revenue Funding, which are discussed in detail below.

Notably, there were a number of blockages identified that in essence mirror the success factors identified under Section 7.1. This indicates that substantial progress can be made where services commit to addressing these blockages and focus on the success factors. These include:

- Tackling ambiguous leadership
- Engaging in active and on-going communication with all stakeholders
- Pro-actively addressing challenges around workforce planning and staff reconfiguration, so that negotiations and/or arbitration through the formal Industrial Relations mechanism do not lead to delays
- Putting in place staff as key "enablers" to support transitions, including Project Managers, Team Leaders or Transition Co-ordinators as required (Delays in the release of Service Reform Funding impacted the filling of these posts in some settings)
- Identifying any on-going revenue funding costs of transitions and exploring options to address this
- Advancing the procurement of support services from third party service providers in line with transition plans

7.4.1 Accommodation Challenges

As new capital funding became available in 2017 there was increased activity in relation to sourcing housing for people moving from the congregated settings. Service providers, Approved Housing Bodies, HSE Estates and other stakeholders including the Department of Health, DHPLG and the National Social Care Division all worked to ensure that suitable homes for people with disabilities could be secured. New processes and structures were put in place to support this work and streamline activity, but a number of challenges persisted as well as some new ones emerging. These included:

- Difficulty in sourcing and securing suitable affordable housing to purchase or rent,

through all the mechanisms available

- The time needed to complete the purchase, adaptation of properties in line with the various relevant regulations and professional advice (Procurement Regulations, Building & Planning Regulations, Fire Codes, OT assessments)
- Variations in relation to the level of equipping and refurbishment planned due to differing professional opinions on the interpretation of regulations, fire safety and equipping requirements
- The time taken to secure the certification of homes as designated centres under the regulations.

Lead- in time for HSE Capital Funded projects

Evidence from the projects funded through the HSE Disability Capital Programme demonstrates that there is a significant lead in time in providing accommodation to enable transitioning. The sourcing and purchasing of properties, the planning and procurement of refurbishments and adaptations, along with the completion of any necessary works, fit out and furnishing, all contribute to this. Data confirms that this process is consistently taking up to 12 months. The HSE Estates & Oversight group continues to monitor progress of projects to ensure that where possible streamlining of the processes can be facilitated.

Importantly, whilst a house may be reported as "operational" from a capital perspective, there may also be an additional period of time required to secure registration and/or to enable the services to support each resident to transition, which can be an incremental process based on the person's needs and wishes. Where there are a number of residents moving transitions are sometimes staggered, so that each person is given the opportunity to settle before the next resident moves in. For some residents their transition plan involves gradually increasing the time they spend in their new home before making the final permanent move to the new location.

Accessing Capital Assistance Scheme (CAS) Funding

The uptake under the CAS funding stream for 2017 remained low with only 10 projects approved at a total cost of 3.9 million for 41 individuals, which equates to €95,000 per person.

There is on-going engagement between the stakeholders to improve the uptake of the CAS funding to support decongregation. Towards the end of 2017, a series of meetings chaired by the DHPLG were held with key personnel from the HSE, Housing Agency and DOH to address a number of technical issues that have come to light in relation to the cost of some

projects. A joint Circular is being developed by the DHPLG and the HSE that will provide guidance and ensure that there is clarity for the local authorities, AHBs and service providers on the scope of the CAS funding in relation to the costs and level of adaptations that occur in social housing projects for people with disabilities.

Property Adaptation

The 2016 Annual Progress Report detailed the challenges arising in relation to determining the appropriate level of adaptation and refurbishment needed in specific properties and the cost and time implications of this. During 2017 the HSE Disability & Estates Oversight group developed guidance to support the local services and HSE teams to manage these issues.

As detailed in Chapter 3, Section 3.2.3, a *Making Homes* work stream commenced in 2017 to develop a guidance document that will signpost best and appropriate practice in the adaption and refurbishment of properties for people moving to the community. It will focus on supporting providers to deliver a "home" for individuals rather than creating a mini-institution or medical care setting. The "Making Homes" document will be finalised in mid-2018 and added to the Implementation Framework as a resource for providers and staff.

Impact of Regulation by HIQA

Under current legislation all new residential settings that are deemed to meet the criteria for registration as a "designated centre" must be fully registered by HIQA before they can be occupied. Initially the registration and inspection process that started in 2013, pulled the focus of providers away from transition plans, as achieving compliance became the priority.

However, more recently the priority sites report that HIQA have worked with them to facilitate the registration of new centres promptly which has supported the focus on transitioning residents to person centred models of care in the community. Local services have reported on the positive rapport that has been established with local inspectors and the pro-active approach taken in relation to new projects.

Unfortunately delays have still arisen that impact planned transitions. In all cases these were resolved, but it is important to note that for the residents, their families, support staff and the service provider, an unexpected delay can cause distress and disruption, particularly where carefully co-ordinated and time-bound plans have been put into action.

7.4.2 Communication Challenges

The importance of supporting meaningful communication and engagement as part of the *Time to Move on* change programme cannot be under-stated. This will continue to be one of the most critical areas in supporting the delivery of the policy.

Supporting the Residents and their Families

There is substantial evidence from the service providers that the communication and engagement process must be on-going and actively managed at a local level. This needs to include the individuals, their families and other stakeholders such as neighbours, friends, community groups etc. who can also have a critical role in ensuring a person's transition is well-supported. This requires on-going and continuous attention at all stages of the transition journey in particular in relation to:

- Focussing on and emphasising the gains for the person moving to the community
- Acknowledging and supporting people to address any sense of "loss" that can arise when leaving the congregated setting
- Addressing the specific concerns of each person and their circle of support
- Working with other interested stakeholders

Co-ordinated efforts by the service provider team and a willingness to provide support and information as required will continue to be critical in supporting good communication as an enabler to the successful implementation of the policy.

Supporting staff who work in congregated setting

Staff have a crucial role in the decongregation process and their input will impact how and when the policy is implemented and most importantly it will influence the outcomes for the residents. During 2017, there was a focus on the priority sites and examining the "distance travelled" in these settings, particularly as there had been financial investment through the SRF and capital investment. The experience in these settings shows that the approach taken to supporting staff can significantly influence the progress made.

Where services provided clear leadership and focussed on staff development and team building, there was evidence of a marked change in culture, with the model of practice shifting from more institutional and medical or nurse-led models of care to a social care model in which the person being supported is at the centre. In these settings there is

evidence of changes in team and working relationships, a re-alignment of roles with frontline staff emerging as champions and examples of practice that is both innovative and person-centred. Much of this was achieved by putting in place dedicated change managers / project leaders and a small team of staff who worked directly with residents. These change teams were fully supported by the service to bring about change, which included training / up skilling and operational autonomy with regard to resources and supports.

In some other services far less progress is evident and the shift from traditional attitudes and models of care has been much slower. An examination of the reasons underlying this showed that whilst staff may be equally as diligent and committed to providing a high quality service, staff within a service do not have the capacity to bring about meaningful change on their own. The obstacles to achieving this include ambiguous leadership and a lack of investment in training and on-going support of staff to enable them to implement and embed new practice models.

7.4.3 Revenue Funding challenges

A key feature of the transitions commenced and achieved in 2017 is that additional revenue costs are being identified as a requirement to support the transitions. The challenges of introducing new models of service and the impact of on-going additional revenue costs are discussed below.

Service Reform Fund -Supporting Change through Leaders & Frontline staff

The 2015 Progress Report referenced the need for strong leadership, governance and planning, noting that where this is in place, *"projects do progress and the majority of the issues that arise can be managed and resolved without significantly hampering or undermining the transition process"*. The report went on to note that leaders need to be supported both within and outside the organisation.

During 2016 ten priority sites were supported to develop proposals for funding from the Service Reform Fund that would support them to drive forward a new model of person centred supports and move away from the traditional model of residential services. A key component to the proposals was the identification, recruitment and training of leaders who would hold a project manager role along with a number of frontline staff who would work directly with the residents and champion the new model of service. The proposals

demonstrated that there is a significant difference across the settings in relation to how providers plan to develop and deliver a person centred model of support in the community.

Many of the service locations also released staff to undertake the Supported Self Directed Living (SSDL) training delivered by the Genio Trust. This training supports staff to understand this approach to working with people with disabilities and embed this into their day to day practice through practical work between the training sessions.

Unfortunately in 2016 delays arose in releasing some of the SRF funding. During 2017 the SRF proposals were revisited and funding was allocated to a number of sites. This funding should have a direct impact on supporting the transition process during 2018 helping to build capacity within the congregated settings workforce and support services to embed good person-centred practice that brings about meaningful change as people transition out.

On-going Revenue Funding

The original report suggested that the funding for the disability services at the time in 2009 was adequate to enable service providers to meet the cost of delivering supports for the population moving from congregated settings, once their moves to the community had been completed. In 2017 this statement is no longer considered valid for a number of reasons including:

Deficits in Existing Settings

The HIQA inspection process continues to identify congregated centres where the quality and standard of care provided is not adequate. Many of the service providers do not have sufficient resources to address environmental issues, to deliver safe care or to enable individuals to access supports /activities on an individual or group basis. Additional investment is required in these services to address the deficits without advancing any move to community living. There is a dilemma in relation to the need for funding to be spent on improving congregated settings that are not fit for purpose, but where people currently live, rather than being able to invest this funding in building homes in the community.

Changing Need

The profile of the residents in congregated settings has changed; they are now an older group with more complex support needs. This is supported by changes identified in the

TILDA Wave 3[1] research published in December 2017 which details that:

- As expected with an ageing cohort, there was increased health service use since previous waves with increases in particular in emergency department admissions, GP use, outpatient appointments and hospital admissions *(page 108)*
- Overall there was an incidence of 4.7% of dementia between Waves 2 and 3 in the total population. Of the people who received a new diagnosis of dementia between Waves 2 and 3, 74% had Down syndrome *(page 80)*
- For people with Down syndrome the average age of diagnosis of dementia was 52.3 years compared to 65.5 for those with intellectual disability from other aetiologies *(page 82*)
- For those with Down syndrome, prevalence of epilepsy without dementia was low at 14.5%; however among people with Down syndrome with dementia, the prevalence of epilepsy rose to 54.8% *(page 83)*

All of these changes will bring new challenges and increased pressure for additional resources to meet the needs of residents.

New Directions

The Time to Move on policy states that people transitioning from congregated settings will be supported to access a meaningful day. Consideration has to be given as to how people in residential services will be supported to access the New Directions model of day services as outlined in the National Review of HSE Funded Adult Day Services 2012. New Directions sets out twelve supports that should be available to people with disabilities using 'day services'. It proposes that 'day services' should take the form of individualised outcome-focussed supports to allow adults using those services to live a life of their choosing in accordance with their own wishes, and aspirations.

It is accepted that additional revenue funding is required to implement New Directions across the disability sector. On this basis, there is likely to be a cost implication for each person who transitions to the community and requires support in line with the New Directions model. This will particularly be the case for individuals moving to the community that previously had little or no access to a day service and/or where there are no day service resources available for reconfiguration to support the person to enjoy a "meaningful day". There are now challenges as services examine how best to reconfigure existing day and residential

[1] Health, Wellbeing and Social Inclusion: Ageing with an Intellectual Disability in Ireland
Evidence of the First Ten Years of the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA)

services to support people moving to the community and how to move away from a traditional day service and introduce a New Directions approach within resource and other service capacity limitations.

8. Priority Actions and Work Plan for 2018

8.1 National Service Plan 2018

The HSE 2018 *National Service Plan* (NSP) prioritises progressing the Time to Move on policy and the development of our workforce to ensure the delivery of a person-centred social model of care. Specific actions include supporting 170 individuals to move to community based service models and improved compliance with the national residential care standards as regulated by HIQA. The HSE will also continue to realign the workforce to deliver a person-centred social care model with a specific focus on achieving this in congregated settings.

8.2 Detailed Actions relating to "Time to Move on" in 2018

The 2018 work plan for *Time to Move on* Subgroup sets out a number of actions to continue to support the implementation of the policy. The work plan details identify national, CHO and service provider activity targets which will drive implementation and facilitate oversight of the policy throughout 2018.

The subgroup work plan includes:

- Cross sectoral engagement with the Department of Health, HSE and DHPLG to develop guidance on housing issues
- Continued development of communications around the policy and develop of positive stories for print /video
- Completion of a proposal for development of information hub with the support of a Research Officer
- Finalising the report of the Location Review work stream
- Establishing a work stream to improve connectivity with New Directions for people currently in and those leaving congregated settings
- Complete and disseminate the "Making Homes" guidance document.

9. Conclusions & Next Steps

The Time to Move on policy was implemented in 2012 and had "*a seven-year timeframe for the overall national closure programme for congregated settings...*" It is now recognised that full implementation of the policy will not be achieved in this timeframe. The 2016 *Programme for a Partnership Government* identified a revised target of achieving a one-third reduction of the numbers remaining in congregated settings by the year 2021. This demonstrates an on-going commitment to delivering the policy and recognises the complexity of the task and the need for a sustainable and steady pace of change to be achieved.

Progress in implementing the policy over the past 6 years has led to the complete closure of several congregated settings and the significant reduction in the population remaining in others. Many individuals are now being supported to live a life of their choice out in the community. For those still in congregated settings, in many cases there has been a reduction in the overall number of residents, leading to many of the individuals now having access to better living conditions, with improved facilities that they share with a smaller number of people.

Challenges that arose during 2017 and impacted on the progress of targeted transitions included:

Housing / Funding

- Finding and securing suitable affordable housing in an increasingly buoyant housing market
- Time required to complete the purchase, adaptation and registration of properties in line with the various relevant regulations and professional advice (Procurement Regulations, Building & Planning Regulations, Fire Codes, OT assessments, HIQA Regulations)
- Difficulty in accessing housing through other mechanisms outside of the HSE Disability Capital Funding Programme, such as the Capital Assistance Scheme or through direct supply from local authorities or private landlords

Revenue

- Difficulty in meeting on-going revenue funding costs of transitions (sustainable budget position) alongside pay bill management and costs associated with achieving regulatory compliance and registration.

Organisational / Staffing

- Putting in place staff as key "enablers" to support transitions
- Delays in recruiting/releasing appropriate staff
- Need to address the changing needs of residents, which required a late adjustment to the staffing levels and skill mix required to support transitions
- Several services encountered delays at a local level as a result of proposed changes to staffing arrangements. This required them to negotiate with trade unions and to refer specific issues through the Industrial Relations mechanism for resolution.

Housing is a significant first step in supporting individuals to move into the community and all the additional capital resources announced and provided during 2017 are an essential "enabler" for the policy. For the coming years it will be necessary to focus on delivering housing options and supporting the service providers and all other stakeholders to unblock the challenges in securing appropriate good quality accommodation. This will ensure people with disabilities are enabled to transition into homes of their own on a long-term basis funded from the capital resources available over the next five years.

However it must be recognised that housing is just the first hurdle. It is critical that the service providers, supported by the local CHO team, proactively manage and remain vigilant to the other challenges that will emerge as the housing solutions fall into place. Communication will be critical in managing individual and family uncertainty, staff concerns and HR issues, revenue funding issues, day to day governance issues and leadership capacity.

There was evidence in the 2017 Project Action Plans completed by the priority sites that the commitment and momentum towards implementing the policy continues to grow. This was also evident from the updated SRF proposals and presentations that took place in October and November 2017. However the lack of progress in some locations and the significant concerns following HIQA inspections indicates that there are still significant issues to be overcome.

As outlined in the 2016 report a commitment to deliver change and a strong partnership approach between the CHO and the local service provider are essential enablers that support the implementation of the policy. The provision of funding in 2018 to support emergencies and develop respite services will help to reduce some of the pressures across

disability services and sustain the momentum and resourcing of transition plans. There will continue to be a need for close collaboration between the CHO and the service provider to ensure that transitions are carefully planned and appropriately supported. Without this, there is an increased risk that moves will be made without the appropriate level of support or resources, which can negatively impact on the transition. Services must remain vigilant to ensure the best outcome for the individual, their family and the staff involved. Positive transitions can create a buzz that positively influences others and effects a change, whereas poor communication can damage the relationship between the stakeholders and undermine support for future decongregation plans.

The HSE Disability Strategy and Planning Team (formerly the Reform Team) and the Time to Move on Subgroup will continue working to support service providers, HSE colleagues in the CHO teams and other stakeholder groups through the development of resources and supports that will progress the policy and ensure the best outcome for each person that moves. Priorities will include the delivery of a multi-annual plan for the allocation of capital resources, transitional resources (SRF) and the management of activity targets, to ensure that providers can effectively plan the implementation of the policy over a number of years.

Appendix 1: Progress on implementing *Time to Move on* Report

In Table A1 below the original report recommendations are listed. The status of each recommendation is given along with a commentary on the activity completed or still on-going to address the particular recommendation.

Table A1: Detailed Review of Report Recommendations and current status

No.	Responsible body	Recommendations	Status	Actions to Date
1	Department of Health	The Department of Health should issue a vision and policy statement on the closure of congregated settings and transition of residents to community settings.	Complete	
2	Department of Environment (2017 Dept. of Housing, Planning and Local Government)	The Working Group's proposals should be reflected in the National Housing Strategy being prepared by the Department of Environment, Heritage and Local Government.	Complete	The National Housing Strategy for People with a Disability (NHSPwD) 2011-2017 was published in 2011 and remains an active strategy.
3	HSE	A named senior official of the HSE should be charged with driving and implementing the transitioning programme, assisted and guided by a National Implementation Group. The Department of the Environment, Heritage and Local Government should be represented on the National Implementation Group.	Complete	A National *Time to Move on* Subgroup is in place under the Transforming Lives Programme, which is charged with driving the implementation of the policy and providing support and oversight. . This is a multi-stakeholder, cross-departmental group, chaired by a member of the National Disability Reform Team.

No.	Responsible body	Recommendations	Status	Actions to Date
4	HSE	A manpower strategy to support the programme of transition to community settings should be devised by the National Implementation Group in partnership with key stakeholder groups. The strategy should address staffing requirements and skill mix needs for community inclusion, skill development and professional development requirements, and the human resource aspects of the transition programme.	On-going	Supporting people to move into the community can require significant re-organisation of the staffing resources within a service, including the up skilling, retraining and development of staff to support a social care model. The nature and extent of the re-organisation required will be dependent on the existing model of service and supports and those determined as appropriate to support the people moving to the community. The Project Action Plan supports and guides Service Providers in regard to the key areas that need to be addressed when reconfiguring services including HR and Workforce planning, Training, delivering Community inclusion, Finance, Governance, Leadership and Communication, all of which are areas that will form part of the manpower strategy that each provider needs to develop for their specific service. On-going work may be required at a national level to ensure best practice and consistent HR approaches and solutions are developed and adopted where appropriate to support individual services.
5	HSE	A Working Group should be set up to co- ordinate the development of a range of protocols to ensure a co-ordinated approach to community inclusion for people with disabilities. These protocols should be developed across key government departments and agencies, in partnership with the National Implementation Group; they should be prepared within the framework of the National Disability Strategy and have regard to the Sectoral Plans prepared under that Strategy.	On-going	A Community Living Transition Plan toolkit is available to support service providers in the development of project/ transition plans for individuals moving to more socially inclusive settings. It aims to: • Inform and guide organisations when supporting people to develop their plan to move into the community • Set out the key ingredients required within these plans to ensure that the person is fully supported and assisted to have a successful and sustainable move into the community • Inform and guide the local / regional implementation teams when reviewing organisational plans to ensure that all community transition plans meet the requirements for successful transition planning. Resources continue to be developed to support and guide Service Providers in regard to the key areas that need to be addressed when reconfiguring services, which include a focus on delivering community inclusion.

No.	Responsible body	Recommendations	Status	Actions to Date
6	HSE	A change management programme to support the transitioning programme should be developed and resourced. The change management plan should be executed by HSE and overseen by the National Implementation Group.	On-going	The Transforming Lives" Programme in the Disability Services was established in 2014 under the HSE System Reform Programme. The *Time to Move on* Subgroup was established under this Programme to further drive the implementation of the policy. This is a multi- stakeholder, cross–departmental group which has been delivering on a clear work plan to support the implementation of the policy during the period 2015 -2019. A Project Action Plan tool and other resources are in place that supports and guides Service Providers in regard to the key areas that need to be addressed when reconfiguring services, including change management. A number of sites have been identified and prioritised for support which includes access to both capital and transitional revenue funding under the Service Reform Fund. Nationally, support and oversight of the local change management plans developed with national guidance is in place. Work is on-going to improve public communication and promote positive messages. In 2017 there was a number of learning events and workshops with providers as well as site visits and engagement with individual change teams.
7	HSE	The provision of accommodation for people moving from congregated settings to their local community must be broader than a plan for accommodation; accommodation arrangements for housing must be part of a new model of support that integrates housing with supported living arrangements. The new model of support should be based on the principles of person-centeredness; it should enable people with disabilities to live in dispersed housing, with supports tailored to their individual need.	Complete	Recommendation 5 above also refers. All resources developed by the National TTMO Group identify that the transition plan for an individual requires a person-centred plan that focuses on delivering for each person a "meaningful life of their choosing in the community" and is not just around housing and residential supports. The criteria for projects under the HSE disability capital funding and CAS funding support this, by requiring an assurance that accommodation is person centred and will support delivery of individual plans.

No.	Responsible body	Recommendations	Status	Actions to Date
8	HSE	All those moving from congregated settings should be provided with dispersed housing in the community, where they may: • Choose to live on their own • Share with others who do not have a disability • Share their home with other people with a disability • Live with their own family or opt for long-term placement with another family	Action Complete: Delivery on-going	The Community Living Transition Plan Toolkit supports services to identify each person's preference in terms of their future housing choice. Under the *Time to Move on* Subgroup a dataset has been developed that captures the future housing need of each person currently in a congregated setting and tracks the movement of individuals to ensure that appropriate housing solutions are implemented. The revised Housing Circular (45/2015) and CAS Call (29/2017) in place now ensures that accommodation sourced through this funding mechanism is now person-centred, dispersed and in keeping with individual plans. Capital resources of €100million have been allocated from 2017-2021 to support the transitions from congregated settings. The HSE at a national level to ensure the allocation of capital resources is in keeping with the *Time to Move on* policy in terms of clustered /dispersed housing and delivery of person centre plans.
9	HSE	Where home-sharing with other people with a disability is the housing option chosen by the individual, the Working Group recommends that the home-sharing arrangement should be confined to no more than four residents in total and that those sharing accommodation have, as far as possible, chosen to live with the other three people.	Complete	The HSE has a process in place to oversee new developments / property acquisitions across the sector and ensure this recommendation is implemented. It can be noted that some residents are transitioning from congregated settings to pre-existing community group homes that are not congregated settings but do have more than four residents. The HSE takes a pragmatic view in supporting this approach, once it is • In line with the person's individual person centred plan • Facilitates a step down approach for those that are transitioning and may not be ready to move to more independent or individualised arrangements • Utilises more appropriate available accommodation.
10	HSE	Supported living arrangements should enable the person to choose to: • Decide on, control and manage their own supports • Contract with a third party to help with the management of their individualised support package • Choose to combine resources with others to pay for shared supports as well as having some personalised supports	Action Complete: Delivery on-going	The Community Living Transition Plan toolkit and other resources support service providers to identify and develop supports that are self-directed, person-centred and individualised. A Person Centred Planning Framework is being developed which will support choice and self-direction. A Taskforce on Personalised Budgets (PBs) is in place to examine the delivery of PB in the disability sector, which will expand the options currently available to service users.

No.	Responsible body	Recommendations	Status	Actions to Date
11	HSE	People with disabilities living in dispersed accommodation in community settings will need a range of support programmes to help them to plan for their lives, and take up valued social roles.	Action Complete: Delivery on-going	A Project Action Plan tool and other resources are in place that supports and guides Service Providers in regard to the key areas that need to be addressed when reconfiguring services, including individual planning and community inclusion. A number of sites have been identified and prioritised for support which includes access to transitional revenue funding under the service reform fund and SSDL and SRV training with Genio Trust. Nationally, support and oversight of the local implementation plans is in place to ensure changes in practice are embedded.
12	HSE	Action is required by HSE to strengthen the capacity of community health services to deliver supports to people with disabilities.	On-going	A communication strategy is in place that identifies the need for local engagement to ensure the community health service can respond to the needs of those moving out of congregated settings and accessing community supports in their area. A mechanism for the management or escalation of blockages and issues nationally is in place.
13	HSE & Department of Environment, Heritage and Local Government and local authorities	The HSE should provide for the health and personal social needs of residents moving to the community while responsibility for housing rests with the Department of Environment, Heritage and Local Government and local authorities.	No further action required Delivery on-going	The HSE has the remit for the provision of health and personal social supports for people with disabilities. Meeting the needs of individuals as they move into the community, can require a co-ordinated approach, as individuals are supported by professionals from social care, primary care, mental health and other specialities depending on their needs. The disability service providers are working in collaboration with the local authorities, Housing Agency, approved housing bodies and DHPLG with regard to addressing the housing needs of people with disabilities. See also Recommendation 18, 19, 20
14	HSE	Governance, management and delivery of in-home supports should be separate from provision of inclusion supports, to ensure that the person with a disability has maximum choice of support providers and maximum independence.	No action planned Delivery on-going	Currently a person's residential and day services supports may be integrated or delivered separately depending on the configuration of the service providers and/or whether both services are delivered via one provider. As service providers re-configure to enable de-congregation from congregated settings and build their capacity for community inclusion, opportunities will develop for greater separation of in-house and community -inclusion supports. This will also link with the development and roll out of the New Directions Day Services model of supports and the development of supports from the wider community services.

No.	Responsible body	Recommendations	Status	Actions to Date
15	HSE	The individualised supports for people with disabilities should be delivered through a co-ordinating local structure based on defined HSE catchment areas, within which the full range of supports is available.	To be progressed	The Community Living Transition Plan toolkit and other resources support service providers to identify and develop supports that are self-directed, person-centred and individualised. In the priority sites, project managers oversee the work of community connectors and transition co-ordinators that support individuals to access appropriate supports. To date there has been no national roll-out in relation to the development of local co-ordinating structures which can support local area co-ordination and capacity building. This will benefit providers, as it will help to identify and address the gaps in service provision and promote collaborative working. .
16	HSE	A study of the feasibility of introducing tendering for services should be undertaken by HSE to examine its potential in an Irish context.	On-going	The 2015 Social Care National Operational Plan identified as an action that a procurement framework would be implemented for the procurement of services including residential places from Private for Profit organisations. This work has been completed in relation to individual placements and is informing the process being undertaken at a local level when negotiating individual service provision. Further work is currently on-going in relation to personal budgets under the Taskforce on Individualised Budgets.
17	HSE	Funding currently in the system for meeting the needs of people in congregated settings should be retained and redeployed to support community inclusion; any savings arising from the move should be used for new community based services.	In hand: Delivery on-going	The funding for residential services in the non-statutory providers is identified and managed under the Service (Provider Governance) Arrangements. Under these arrangements the HSE ensures that allocated funding is appropriately managed to support the delivery of the agreed quantum/type of services.

No.	Responsible body	Recommendations	Status	Actions to Date
18	HSE	The accommodation needs of people moving from congregated settings should be met through a combination of purchased housing, new-build housing, and leased housing or rented housing. .	Action complete: Delivery on-going	The National Housing Strategy for People with Disabilities Steering group is actively engaged in finding solutions to deliver housing that meets the needs of people with disabilities. This has included supporting a number of innovative pilot projects through the social leasing funding, to demonstrate the viability of alternate funding arrangements for social housing. Initiatives continue to be recommended and supported in that demonstrate the range of housing solutions. The *Time to Move on* working group developed a housing options document in 2017, to capture for providers all the current funding mechanisms and options available for securing housing. The HSE has completed the 'Housing Need' profiling exercise to determine what resources are required to support people in congregated settings to access appropriate accommodation of their choice. This has identified the demand for the various funding mechanisms and the likely timescale of proposed projects. The data will be shared to inform discussions with DHPLG and the HDSGs, particularly in terms of the viability and demand for social leasing options, CAS funding and other funding mechanisms.
19	HSE and Government	There will be instances where purpose built new housing in the community to meet particular individual needs will need to be built, or purchased and made accessible Where agencies providing congregated settings may be disposed to sell land to help to fund new accommodation, and need short/medium term financing to enable accommodation to be built or purchased for residents before property and land can be sold, this short-term funding should be provided by the state by way of loan.	To be progressed	€100 million capital funding has been allocated to support the transitions from congregated settings. This recognises that in some instances purpose built housing will be required. In 2017, €20million was allocated to priority projects for housing for 165 residents. The HSE at a national and area level is ensuring the appropriate allocation and arrangement for disbursement and management of capital resources in keeping with the *Time to Move on* policy, National Financial Regulations and relevant Capital Management processes. Recommendation for bridging loan arrangement requires attention

No.	Responsible body	Recommendations	Status	Actions to Date
20	Department of Social Department of Environment, Heritage and Local Government, and the Department of Health	All those making the transition from congregated settings should be assessed for eligibility for Rent Supplement or Rental Accommodation Scheme. This subject needs detailed consideration by the Department of Social Protection, Department of Environment, Heritage and Local Government, and the Department of Health and Children.	Complete	The National Housing Strategy Subgroup includes cross sectoral representation from the Department Of Health, DHPLG, HSE, Housing Agency, and a number of other stakeholders. Nationally, the group have developed guidance for housing authorities as to how they can support people with disabilities to seek access to social housing and housing support schemes. The process for accessing social housing is being implemented in all areas using the agreed pathway.
21	HSE	A local re-housing plan should be prepared and jointly co-ordinated by local authorities and HSE, in collaboration with service providers. The plan should be based on best practice in including people with disabilities in local communities and should facilitate dispersed housing with personal supports. All residents in congregated settings should be assessed by housing authorities to establish their eligibility and need for social housing support. Service Providers should ensure that their clients are assessed for housing by the relevant local authority.	Action Complete: Delivery on-going	The *Community Living Transition Plan* Toolkit and the *Housing Options* document supports services to identify each person's preference in terms of their future housing choice. Housing authorities are working in collaboration with the HSE and service providers to identify and plan for the housing needs of people with Disabilities through the local authority NHSPwD groups. Each housing authority has drafted a 5 year Strategic Plan for the delivery of the NHSPwD ,which identifies all the current and future housing need in their area, including individuals resident in congregated settings. A review of the wait list of those PwD identified as having a housing need in each local authority is now being undertaken to hone the wait list further and deliver better strategic planning.
22	Department of Environment, Heritage and Local Government	Housing authorities should give consideration to reserving a certain proportion of dwellings for people with disabilities. A suite of letting criteria specific to housing for people with disabilities should be developed and reflected in a national protocol.	In hand: To be progressed	Under the NHSPwD, the Housing & Disability Steering Groups established in each local authority area have drafted a 5 year strategic plan to examine how the housing need of people with disabilities can be met in their area. DHPLG to examine the suite of letting criteria.

No.	Responsible body	Recommendations	Status	Actions to Date
23	HSE	A seven-year timeframe for the overall national closure programme for congregated settings should be set. Within that timeframe, specific annual targets should be set at national and local level to guide the phasing and prioritising process, in consultation with the HSE	Complete	The Programme for a Partnership Government sets a revised target of a one third reduction by 2021, in recognition that the rate of progress is slower than the target set in the original report. Annual targets are in place and identified in the HSE National Service Plans and the HSE Capital Disability programme.
24	HSE	An implementation team should be set up at Integrated Service Area level within HSE and a named person given responsibility for supporting the transfer of people into the community; this person should be responsible for ensuring that local public and voluntary services are prepared to respond to the development of a comprehensive community support infrastructure.	To be progressed	In line with the reconfiguration of the HSE into nine new Community Health Organisations, the development of revised structures linked to the Time to Move on subgroup will be rolled out in due course to support the implementation of the policy in the future.
25	HSE	All agencies currently operating congregated settings should be required to submit their transitioning strategy to HSE, with detailed operational plans, timeframes and deadlines, based on the review recommendations. Agency proposals should be part of annual discussions with HSE in respect of service agreements.	Complete	The project action plan documentation suite was developed and launched in 2016 to support all service providers to develop plans to identify how the transition of service users from their congregated services to more socially inclusive settings would be achieved. Each year there is a focus on supporting the priority sites to develop and deliver plans using the template documentation. These plans are reviewed by the National Social Care division and CHO team locally.
26	HSE	A number of ***Accelerated Learning Sites*** should be funded to provide ambitious and accelerated implementation of the policy and robust examples of evidence-based transitions to models of community living.	Complete	The key learning from an initial group of accelerated sites was collated and shared in 2015. This included projects funded by Genio (accelerated learning sites) and any other projects that had completed the transition process. On an on-going basis, the Time to Move on Subgroup continues to gather information from services that have completed transitions to enable on-going shared learning.

No.	Responsible body	Recommendations	Status	Actions to Date
27	HSE	A range of new funding streams should be brought together in a Congregated Settings Fund	On-going	See Recommendation No 6, 8, 19 and 29. There are a range of funding streams currently in place to support the implementation of the Time to Move on from Congregated Settings policy (HSE Capital, CAS, SRF, some targeted HSE revenue funding) and work is on-going to determine the resource requirements to deliver the policy.
28	HSE	A comprehensive evaluation framework for the transitioning project should be agreed at national level to ensure a standardised approach to evaluation across all Accelerated Learning Projects and other settings involved in transitioning to the community, and an agreed minimum data set. The evaluation framework should be agreed prior to start of any project. It should be informed by similar work conducted internationally. In order to ensure the integrity of the evaluation in each site, an independent agent should undertake this evaluation across all participating sites.	Action complete: Delivery on-going	Projects funded through the Genio Trust have undergone a comprehensive evaluation, which has provided documented findings and learning for the sector, see Recommendation 26. Under the remit of Working Group 1 in the "Transforming Lives" Programme, an individual pre and post transition outcome assessment tool has been developed and is being implemented, that will evaluate the impact of the policy on individuals. The Project Action plan documentation provides a framework for the evaluation of projects against key themes and work strands. During 2017 this was introduced and an Oversight group was established to evaluate plans and provide feedback.
29	HSE	Resources should be made available as part of the change management planning to support people with disabilities, families, and staff to transfer to the community and to develop community readiness.	In hand: Delivery ongoing	To date, additional resources have been targeted at the priority sites. The allocation of these resources is being managed to ensure service providers address the multiple elements involved in decongregation and the building of community capacity and supports, to ensure people transition to meaningful lives in the community. In 2016, a number of Local Area Co- Ordination initiatives were resourced through the Dormant Accounts Fund to focus on building community capacity. These projects are now completed. In 2016, a number of sites were prioritised for support from the Service Reform Fund (SRF) to meet the costs of migrating to a person-centred model of services and supports. These projects are currently on-going.

No.	Responsible body	Recommendations	Status	Actions to Date
30	HSE	A dedicated and appropriately resourced advocacy provision should be provided over the period of the transfer programme for those moving from congregated settings.	Complete	Advocacy is sourced from the National Advocacy Service, local community support networks and advocacy groups or by service providers working with and supporting family, staff or other people known to the residents to act as advocates. As part of the Community Living Transition Plan toolkit, service providers are directed to ensure there is an appropriate advocate, independent person and circle of support around the individual. The HSE has supported Inclusion Ireland to develop family forums in a number of priority large residential settings around the country to promote and improve family advocacy. Additional resources have been allocated by the HSE Social Care Division to support this initiative.
31	HSE	The HSE should initiate a review of large residential settings for people with disabilities which were outside the scope of the Working Group, for example, people inappropriately placed in Nursing Homes. The aim of the review should be to ensure that residents in these settings can access community-based support and inclusion, in line with the Working Group's proposals for residents of congregated settings	Action complete : Ongoing	The HSE is aware that many people with disabilities reside in Nursing Homes, which are appropriate to their elder care /medical needs. In some cases people may have enhanced supports in relation to their disability support needs. An expert working group, led by the Disability Federation of Ireland carried out a small scale desktop review of people with disabilities aged less than 65 years of age that live in Nursing Homes, to establish which places are inappropriate and which are appropriate based on the primary needs of the individuals identified on the CSAR (common summary assessment report). The findings of the review were shared with the HSE in October 2017. Follow up actions to be agreed. Under the Time to Move on Subgroup work is currently underway on a review of residential services to determine which locations meet the criteria of a congregated setting and examine how the policy is applicable in each location. This will identify appropriate best practice models to meet the residential support needs of individuals with significant specialist support needs.

Appendix 2: *Time to Move on* Subgroup Membership in 2017

Suzanne Moloney, Project Lead, HSE National Disabilities Office (Chair)

Alison Ryan, Disability Federation of Ireland, DFI representative

Mark O'Connor, Inclusion Ireland

Claire Collins, Department of Health (until September 2017)

Dave O'Connor, Department of Health (joined September 2017)

Patricia Curran, Department of Housing, Planning and Local Government

Martina Larkin, Cheshire Ireland, NFPBA representative

Majella Grainger, Cheshire Ireland, NFPBA representative

Brendan Broderick, Muiriosa Foundation, Nat. Fed. of Vol. Bodies representative

Anna Cunniffe, National Disability Authority (until Oct 2017)

Clare Dempsey, St. John of God, Nat. Fed. of Vol. Bodies representative (until September 2017)

Teresa Mallon, St. John of God, Nat. Fed. of Vol. Bodies representative (from September 2017)

Breda O'Neill, St. Margaret's, Nat. Fed. of Vol. Bodies representative

Alison Ryan, HSE Project Support Officer (until April 2017)

Norma Murphy, HSE Project Support Officer (from April 2017)

Appendix 3: Time to Move on Subgroup Work stream Members

Communication Sub Group

- Mark O'Connor, Inclusion Ireland (Chair);
- Claire Collins, Department of Health
- David O' Connor, Department of Health
- Anna Cunniffe, National Disability Authority
- Norma Murphy, HSE
- Alison Hartnett, National Federation of Voluntary Bodies

Moving Homes Work stream

- Alison Ryan, Disability Federation of Ireland
- Patricia Curran, Department of Housing Planning and Local Government
- Veronica Healy, Department of Housing Planning and Local Government
- Ruth O'Reilly, National Disability Authority
- Ashley Tonge, Department of Housing Planning and Local Government
- Aidan O'Connor, HSE Estates
- Majella Grainger, Cheshire
- Keelin McCarthy, Irish Council for Social Housing

Location Review

- Suzanne Moloney, Health Service Executive Chair
- David O'Connor, Department of Health
- Teresa Mallon, St. John of God Services
- Sr. Marian Harte, Daughters of Charity
- Sean Abbott, COPE Foundation
- Mary Lee, Inclusion Ireland
- Aisling Hunt, Health Service Executive
- Vacant, NDA

Appendix 4: Statistical Information Transitions 2017

Age of Residents Transitioned from Congregated Settings during 2017

Age Profile	CHO 1	CHO 2	CHO 3	CHO 4	CHO 5	CHO 6	CHO 7	CHO 8	CHO 9	Total	%
0-18	0	0	0	0	0	0	0	0	0	0	0.0%
18-29	0	0	1	1	3	1	0	0	1	7	4.9%
30-39	2	0	1	4	8	1	5	1	1	23	16.0%
40-49	3	2	2	8	12	1	1	1	0	30	20.8%
50-59	0	5	3	9	8	5	7	13	4	54	37.5%
60-69	0	1	0	5	0	5	1	3	3	18	12.5%
70-79	0	0	0	6	0	3	0	0	0	9	6.3%
80 Plus	0	0	0	2	0	0	0	0	0	2	1.4%
Not Known	0	0	0	0	0	0	0	0	1	1	0.7%
	5	**8**	**7**	**35**	**31**	**16**	**14**	**18**	**10**	**144**	**100.0%**

Degree of Disability of Residents Transitioned from Congregated Settings during 2017

Degree of Disability	CHO 1	CHO 2	CHO 3	CHO 4	CHO 5	CHO 6	CHO 7	CHO 8	CHO 9	Total	%
Borderline	0	0	0	0	0	0	0	0	0	0	0.0%
Mild	0	2	0	0	0	2	0	0	0	4	2.8%
Moderate	1	5	3	12	1	6	5	1	2	36	25.0%
Severe	4	1	4	14	16	0	8	12	7	66	45.8%
Profound	0	0	0	7	14	4	1	4	0	30	20.8%
Physical & Sensory	0	0	0	2	0	2	0	0	0	4	2.8%
Dual Diagnosis	0	0	0	0	0	2	0	1	1	4	2.8%
Not Known	0	0	0	0	0	0	0	0	0	0	0.0%
	5	**8**	**7**	**35**	**31**	**16**	**14**	**18**	**10**	**144**	**100.0%**

Level of Support of Residents Transitioned from Congregated Settings during 2017

Level of Support	CHO 1	CHO 2	CHO 3	CHO 4	CHO 5	CHO 6	CHO 7	CHO 8	CHO 9	Total	%
Low	0	2	0	1	0	1	0	0	0	4	2.8%
Minimum	0	0	0	0	0	2	0	0	0	2	1.4%
Moderate	0	6	0	6	0	8	1	1	1	23	16.0%
High	5	0	3	24	27	5	13	17	6	100	69.4%
Intensive	0	0	4	4	4	0	0	0	2	14	9.7%
Not Known	0	0	0	0	0	0	0	0	1	1	0.7%
	5	**8**	**7**	**35**	**31**	**16**	**14**	**18**	**10**	**144**	**100.0%**

Length of Stay of Residents Transitioned from Congregated Settings during 2017

Length of Stay	CHO 1	CHO 2	CHO 3	CHO 4	CHO 5	CHO 6	CHO 7	CHO 8	CHO 9	Total	%
Less than 1	0	0	0	0	0	0	0	0	1	1	0.7%
1-4 yrs	0	0	0	1	1	1	0	0	0	3	2.1%
5-10 yrs	0	0	1	1	1	3	0	1	0	7	4.9%
11-20 yrs	1	3	0	3	2	5	4	2	2	22	15.3%
21-30 yrs	0	5	1	13	6	3	1	0	0	29	20.1%
31-40 yrs	4	0	2	13	12	2	1	6	0	40	27.8%
41-50 yrs	0	0	3	2	7	2	7	4	3	28	19.4%
50 yrs plus	0	0	0	1	2	0	0	5	3	11	7.6%
Over 80 Years	0	0	0	0	0	0	0	0	0	0	0.0%
Not known	0	0	0	1	0	0	1	0	1	3	2.1%
Total	**5**	**8**	**7**	**35**	**31**	**16**	**14**	**18**	**10**	**144**	**100.0%**

Appendix 5: Statistical Information CHO Residents Remaining 2017

Age of Residents Remaining in Congregated Settings during 2017

Age	CHO 1	CHO 2	CHO 3	CHO 4	CHO 5	CHO 6	CHO 7	HO 8	CHO 9	Total	%
0-18	0	0	1	0	5	3	2	0	0	11	0.5%
18-29	8	2	5	22	10	5	9	0	18	79	3.3%
30-39	21	10	40	87	22	18	48	5	30	281	11.9%
40-49	54	25	59	188	39	27	71	25	67	555	23.4%
50-59	55	24	67	179	25	25	120	42	122	659	27.8%
60-69	32	29	37	101	27	24	110	29	121	510	21.5%
70-79	14	17	14	34	7	16	44	2	66	214	9.0%
80 Plus	2	5	2	11	1	1	6	1	19	48	2.0%
Not Known	1	0	1	1	1	0	6	0	3	13	0.5%
	187	**112**	**226**	**623**	**137**	**119**	**416**	**104**	**446**	**2370**	**100.0%**

Degree of Disability of Residents Remaining in Congregated Settings during 2017

Degree of Disability	CHO 1	CHO 2	CHO 3	CHO 4	CHO 5	CHO 6	CHO 7	CHO 8	CHO 9	Total	%
Borderline	0	0	0	1	0	0	0	0	2	3	0.1%
Mild	2	4	4	67	3	21	14	2	41	158	6.7%
Moderate	59	35	60	204	24	40	143	16	170	751	31.7%
Severe	86	55	119	222	58	18	133	62	195	948	40.0%
Profound	19	2	26	100	51	11	121	24	21	375	15.8%
Physical & Sensory	20	16	15	26	1	27	0	0	0	105	4.4%
Dual Diagnosis	1	0	0	2	0	2	5	0	13	23	1.0%
Not Known	0	0	2	1	0	0	0	0	4	7	0.3%
	187	**112**	**226**	**623**	**137**	**119**	**416**	**104**	**446**	**2370**	**100.0%**

Level of Support of Residents Remaining in Congregated Settings during 2017

Level of Support	CHO 1	CHO 2	CHO 3	CHO 4	CHO 5	CHO 6	CHO 7	CHO 8	CHO 9	Total	%
Low	4	4	5	77	1	11	5	0	37	144	*6.1%*
Minimum	2	0	5	5	0	2	0	0	1	15	*0.6%*
Moderate	33	75	14	136	5	41	63	4	66	437	*18.4%*
High	142	31	168	366	116	60	319	96	312	1610	*67.9%*
Intensive	6	2	34	39	15	5	29	4	25	159	*6.7%*
Not Known	0	0	0	0	0	0	0	0	5	5	*0.2%*
	187	**112**	**226**	**623**	**137**	**119**	**416**	**104**	**446**	**2370**	**100.0%**

Length of Stay of Residents Remaining in Congregated Settings during 2017

Length of Stay	CHO 1	CHO 2	CHO 3	CHO 4	CHO 5	CHO 6	CHO 7	CHO 8	CHO 9	Total	%
Less than 1	3	0	3	14	4	0	3	1	4	32	*1.4%*
1-4 yrs	13	8	12	26	13	1	10	4	28	115	*4.9%*
5-10 yrs	14	7	7	29	12	17	11	0	23	120	*5.1%*
11-20 yrs	19	24	47	58	8	59	62	10	74	361	*15.2%*
21-30 yrs	26	60	56	65	21	20	47	9	36	340	*14.3%*
31-40 yrs	42	11	60	66	32	12	35	19	28	305	*12.9%*
41-50 yrs	40	2	35	74	36	4	65	35	59	350	*14.8%*
50 yrs plus	20	0	6	16	0	5	61	26	146	280	*11.8%*
Over 80 Years	0	0	0	0	0	0	0	0	0	0	*0.0%*
Not known	10	0	0	275	11	1	122	0	48	467	19.7%
	187	**112**	**226**	**623**	**137**	**119**	**416**	**104**	**446**	**2370**	**100.0%**

Appendix 6: Profile of Congregated Settings remaining at 31/12/2017

Service Providers and Locations in CHO Area 1			
Service Provider	**Service Areas in CHO**	**Residents as at 31/12/2017**	**No of Centres/Units/Campus's within this Service Area**
Cheshire Ireland	Cheshire Letterkenny	11	1 centre, Letterkenny , Co Donegal
	Cheshire Sligo	9	1 centre, Sligo town
HSE	Donegal -Inbhear na Mara	10	1 centre, Bundoran , Co Donegal
	Donegal – JCM Complex	16	1 centre, Carndonagh, Co Donegal
	Donegal – Cill Aoibhinn	8	1 centre, Kilymard , Co Donegal
	Donegal – S.O'Hare	5	1 centre, Stranorlar, Co Donegal
	Sligo - Cloonamahon	42	1 centre, Collooney, Co. Sligo
	Sligo Cregg House	86	20 centres on campus, Ballincar, Co Sligo
2 providers	**8 Service Areas**	**187**	**27 Units/Centre**

Service Providers and Locations in CHO Area 2			
Service Provider	**Service Areas in CHO**	**Residents as at 31/12/2017**	**No of Centres/Units/Campus's within this Service Area**
Brothers of Charity Galway	John Paul Centre	22	4 centres on campus, Ballybane, Galway city
Cheshire Ireland	Cheshire Galway	10	1 centre, Galway city
	Cheshire Mayo	6	1 centre, Swinford, Co. Mayo
HSE	HSE Mayo - Aras Attracta	74	17 centres on campus, Swinford, Mayo
3 providers	**4 Service Areas**	**137**	**23 Units/Centre**

Service Providers and Locations in CHO Area 3			
Service Provider	**Service Areas in CHO**	**Residents as at 31/12/2017**	**No. of Centres/Units/Campus's within this Service Area**
Brothers of Charity Limerick	Brothers of Charity, Limerick	77	16 centres, campus, Bawnmore, Limerick
Cheshire Ireland	Cheshire Limerick	17	1 centre, Newcastle-West , Co Limerick
Daughters of Charity	St. Vincent's Centre	107	22 centres, campus, Lisnagry, Co. Limerick
	Da, St. Anne's Centre	25	4 centres, campus, Roscrea, Co Tipperary
3 providers	**4 Service Areas**	**226**	**43 Units/Centres**

Service Providers and Locations in CHO Area 4			
Service Provider	**Service Areas in CHO**	**Residents as at 31/12/2017**	**No of Centres/Units/Campus's within this Service Area**
Brothers of Charity Southern	Brothers of Charity, Upton Campus	26	6 centres on campus, Upton, Co. Cork
	Brothers of Charity, Lota Campus	39	12 centres on campus, Glanmire, Co. Cork
Cheshire Ireland	Cheshire, St Laurence, Cork	15	1 centre and apartments on a campus Glanmire, Co. Cork.
	Cheshire, Killarney	11	Apartment complex, Killarney, Co. Kerry.
Cork Association for Autism	Cork Association for Autism		8 centres on campus, Carrigtwohill, Co Cork
HSE	HSE Cork St. Raphael's Centre	56	10 centres, Youghal, Co. Cork. 4 on Campus A ; 5 on Campus B; 1 other separate centre
	Cluain Fhionnain	13	2 units on campus, Killarney, Co Kerry
COPE Foundation	COPE Foundation	351	9 centres Campus A, Montenotte, Cork
			3 centres Campus B, Montenotte, Cork
			7 centres Campus C, Hollyhill, Cork
			13 centres in Cork City locations :Togher (2), Tivoli, Glasheen (2), Deerpark (cluster of 7), Turners Cross
			13 centres in County Cork locations: Midleton, Skibbereen, Macroom, Fermoy, Kanturk, Ballincollig , Clonakilty (3) , Bandon (2), Mallow (2)
St John of Gods	St John of God, Kerry Services, Beaufort	75	11 centres on campus, Beaufort, Co. Kerry.
St Vincent's Centre	St Vincent's Centre	37	2 units on campus, Cork City
7 providers	**10 Service Areas**	**623**	**98 Units/Centres**

Service Providers and Locations in CHO Area 5			
Service Provider	**Service Areas in CHO**	**Residents as at 31/12/2017**	**No of Centres/Units/Campus's within this Service Area**
Brothers of Charity, South	Brothers of Charity, Waterford	11	1 centre, Belmont Park, Waterford
Carriglea Cairdre Services	Carriglea Cairdre Services	35	7 centres on a campus, Dungarvan, Co. Waterford
Cheshire Ireland	Cheshire Tullow	7	1 centre and apartment complex ,Tullow Co. Carlow
HSE	Wexford Residential IDS (WRIDS)	32	3 centres in Co Wexford locations
St. Patricks Centre, Kilkenny	St. Patricks Centre Kilkenny	52	2 Campus's, one of which has multiple units, Kilkenny City
5 providers	**5 Service Areas**	**137**	**14 Units\Centres**

Service Providers and Locations in CHO Area 6			
Service Provider	**Service Areas in CHO**	**Residents as at 31/12/2017**	**No of Centres/Units/Campus's within this Service Area**
Cheshire Ireland	Cheshire Shillelagh	20	1 centre, Shillelagh, Co. Wicklow
Children's Sunshine Home	Children's Sunshine Home	10	1 centre, Foxrock, Dublin
HSE	Southside IDS, Aisling House	13	2 adjacent centres, Maynooth Co. Kildare.
	Southside IDS, Hawthorns	19	5 centres in a cluster , Stillorgan, Co. Dublin
St John of Gods	Carmona	9	1 centre on a campus, Bray. Co. Wicklow
St Margaret's Centre	St Margaret's Centre	11	1 campus, Donnybrook, Dublin
Sunbeam	Sunbeam, Hall Lodge	2	1 centre , Arklow, Co. Wicklow
	Sunbeam, Dunavon	8	1 centre, Rathdrum. Co. Wicklow
	Sunbeam, Roseanna Gardens	13	5 centres in cluster, Ashford, Co. Wicklow
	Sunbeam, Valleyview	14	2 adjacent centres, Rathdrum, Co. Wicklow
6 providers	**10 Service Areas**	**119**	**20 Units\Centres**

Providers and Locations in CHO Area 7			
Service Provider	**Service Areas in CHO**	**Residents as at 31/12/2017**	**No of Centres/Units/Campus's within this Service Area**
Cheeverstown	Cheeverstown House	63	14 centres on campus, Templeogue, Dublin
Peamount Healthcare	Peamount Healthcare	73	17 centres on campus, Newcastle, Co. Dublin
St John of God Services	St Raphael's Centre Celbridge	104	14 centres on campus, Celbridge, Co. Kildare
	Islandbridge	11	1 centre, Islandbridge, Dublin
Stewarts Care	Stewarts Care	165	25 centres on campus, Palmerstown, Dublin
4 providers	**5 Service Areas**	**416**	**71 Units/Centres**

Providers and Locations in CHO Area 8			
Service Provider	**Service Areas in CHO**	**Residents as at 31/12/2017**	**No of Centres/Units/Campus's within this Service Area**
Muiriosa Foundation	Moore Abbey	3	4 centres, campus, Monasterevin, Co. Kildare
St John of Gods	St Mary's Centre	80	15 centres on campus, Drumcar, Dunleer, Co Louth
Muiriosa Foundation	St. Mary's Centre	21	1 unit on campus, Delvin Co Westmeath
2 providers	**3 Service Areas**	**104**	**20 Units/Centres**

Providers and Locations in CHO Area 9			
Service Provider	**Service Areas in CHO**	**Residents as at 31/12/2017**	**No of Centres/Units/Campus's within this Service Area**
Cheshire Ireland	Cheshire, Cara	14	1 centre, Phoenix Park, Dublin
Daughters of Charity	St. Joseph's	96	16 centres on campus, Clonsilla, Dublin
	St. Louise's Centre	53	10 centres on campus, Glenmaroon, Dublin
	St. Rosalie's	8	1 centre, Portmarnock, Co. Dublin.
	St. Vincent's Centre	75	13 centres on campus, Navan Road, Dublin
HSE	HSE, Cuan Aoibheann	10	1 centre, Phoenix Park, Dublin
	HSE, St. Josephs IDS	139	16 centres on 1 campus, Donabate Co. Dublin
			1 campus with multiple units, Oldtown, Co. Dublin
			1 centre, Lusk, Co Dublin
St. Michael's House	Baldoyle	12	1 centre, Baldoyle, Dublin
	Ballymun	39	6 centres on campus, Ballymun, Dublin
4 providers	**9 Service Areas**	**446**	**67 Centres /Units**

Total	**58 service Areas**	**2370**	**312 Centres/ Units**

Appendix 7: Preliminary Commentary and update from "Moving In" Study

The NDA is conducting a large scale study which is exploring the quality of life outcomes and costs associated with the move to models of disability services which are community based and person centred. As part of this study around 150 people living in priority sites for decongregation will be interviewed before and (6-9 months) after they move to the community. While the progress of the decongregation process has been slower than anticipated, a number of moves have taken place, and post-transition interviewing is underway. These interviews have provided some very interesting information, and while we can't yet assume that these findings will hold true for everyone who moves out of congregated settings to the community, for the most part the outcomes have been positive. Many participants have significant communication and/or cognitive deficits and so interviews were conducted with the support of staff or by proxy. The majority of those who have transitioned to the community so far have high support needs. Most of the participants lived in congregated settings for many years before their move to the community- many for decades and several for over 50 years. Two of those included in our post-transition interviews were aged 78 and several others were in there 70s.

The post-transition interviews conducted to date provide evidence of significant and at times transformative changes in quality of life following the move to the community. Community integration has greatly increased, family contact is being promoted, challenging behaviours have reduced with a resultant reduction in medication for some participants.
Many of the staff members we encountered on our visits commented on the ease of the transition process. In one residence we were told that before the move staff in the congregated setting commonly expressed the view that the transition would fail and that the residents would return within a week. In fact, staff reported that to their surprise the residents settled in their new home from the first day and the positive changes in their behaviour have exceeded all expectations. A staff member in one house noted that a psychiatrist described the changes in behaviour of one individual as so fundamental that it was like treating two different people. In another house the example of a resident going to a shop and picking a pair of shoes for himself was given to illustrate the improvement in this man's behaviour- previously staff would have considered it unsafe to bring this man shopping.

The participants now live in environments which are quieter, calmer and safer than before.

Many have transitioned from locked units and some from dormitory style accommodation. The noise level is lower because there are fewer people and because in many cases challenging behaviours have reduced. They now have their own bedrooms and live in a home with usually 3 other persons. Bedrooms provide residents with privacy - a space of their own where they can rest, display family photographs and other personal mementoes. Although some of those who have moved to the community are physically frail many are robust and healthy. These participants now have more opportunities to engage in physical exercise. We heard accounts of a range of physical activities such as hill walking, horse-riding, long walks on beaches and swimming. Staff attribute better sleep patterns and reduced restlessness and challenging behaviours to the increased physical activity.
Since their move to the community some participants continue to attend day centres within the campus where they previously lived. Others only return to the campus on rare occasions or not at all. The move to the community has promoted social integration as participants now access community based services and activities to a far greater extent than in the past. The community activities reported include going to local pubs and coffee shops, attending GAA matches, hill-walking with a local group, as well as sporting activities such as swimming and horse-riding.

In many instances staff report increased family contact since the moves have taken place. Families find it easier to visit in the less crowded, quieter, more homely surroundings. Staff have actively sought to strengthen family bonds. This can be especially difficult when people have spent decades in institutional care and when parents are deceased, but in one case the occasion of the participant's 60th birthday was used to re-establish contact with family members and has resulted in now ongoing contact with siblings. This type of reconnection has been seen in a number of cases in the study.

Overall, the results to date indicate very positive improvements in quality of life for those who have made the move to the community. The results indicate that on-going study of outcomes for those who transition from congregated settings is merited.

Report dated: August 2018

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