



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 2016



TRANSFORMING LIVES

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

Contents

| | |
|--|-----------|
| INTRODUCTION | 4 |
| 1. POLICY BACKGROUND AND NATIONAL CONTEXT | 6 |
| 1.1 TIME TO MOVE ON FROM CONGREGATED SETTINGS | 6 |
| 1.2 UNITED NATIONS CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES (2006) | 7 |
| 1.3 HOUSING POLICY | 8 |
| 1.3.1 <i>The National Housing Strategy for People with a Disability 2011 – 2016</i> | 8 |
| 1.3.2 <i>Social Housing Strategy 2020</i> | 9 |
| 1.3.3 <i>Rebuilding Ireland 2016</i> | 10 |
| 2. CURRENT STRUCTURES SUPPORTING THE IMPLEMENTATION OF THE POLICY..... | 11 |
| 2.1 TIME TO MOVE ON SUBGROUP UNDER THE TRANSFORMING LIVES PROGRAMME | 11 |
| 2.2 NATIONAL HOUSING STRATEGY FOR PEOPLE WITH DISABILITY SUBGROUP | 12 |
| 2.3 HSE ESTATES & DISABILITY OVERSIGHT GROUP | 13 |
| 2.4 HSE DISABILITY TEAM OVERSIGHT GROUP..... | 14 |
| 3. WORK UNDERTAKEN TO DRIVE POLICY IMPLEMENTATION DURING 2016 | 15 |
| 3.1 “TIME TO MOVE ON” IMPLEMENTATION FRAMEWORK | 15 |
| 3.2 SUPPORTING THE POLICY | 17 |
| 3.3 NEW RESOURCE DOCUMENTS | 17 |
| 3.3.1 <i>Provider Action Plans</i> | 17 |
| 3.3.2 <i>Communication Strategy</i> | 18 |
| 3.3.3 <i>National “Time To Move On” Bulletin</i> | 19 |
| 3.3.4 <i>National Time to Move On Webpage and contact address</i> | 19 |
| 3.3.5 <i>Supporting People with Disabilities To Access Appropriate Housing In The Community” Housing Guidance Document</i> | 20 |
| 3.4 ENHANCED QUARTERLY PERFORMANCE TRACKING | 20 |
| 3.5 MASTER DATA SET VALIDATION 2016 | 21 |
| 3.6 SERVICE PROVIDER LEARNING EVENTS & INITIATIVES | 21 |
| 3.7 CENTRE VISITS | 23 |
| 4. CAPITAL FUNDING | 25 |
| 4.1 HSE DISABILITY CAPITAL FUNDING PROGRAMME IN 2016 | 25 |
| 4.2 PROCESS, OVERSIGHT & SUPPORT OF CAPITAL PROGRAMME IN 2016 | 26 |
| 4.3 CAPITAL ASSISTANCE SCHEME GUIDELINES (CAS) | 27 |
| 4.3.1 <i>Potential Projects identified for CAS Funding</i> | 27 |
| 4.4 SERVICE REFORM FUND 2016..... | 28 |
| 4.4.1 <i>Service Reform Fund Priority Sites</i> | 28 |
| 5. POPULATION REMAINING IN CONGREGATED SETTINGS..... | 30 |
| 5.1 TRANSITIONS IN 2016 | 31 |
| 5.2 INDIVIDUALS WHO PASSED AWAY DURING 2016 | 38 |
| 5.3 ADMISSIONS DURING 2016 | 39 |
| 6. STATUS OF CONGREGATED SETTINGS AT END OF 2016 | 42 |
| 6.1 PROFILE OF RESIDENTS REMAINING IN CONGREGATED SETTINGS AT END OF DECEMBER 2016 | 42 |
| 6.2 CHANGES TO CONGREGATED SETTING LOCATION PROFILE BY END OF 2016 | 48 |
| 6.3 CHANGES IN THE LOCATIONS IDENTIFIED FROM 2009-2016..... | 48 |
| 6.4 REVIEWING SETTINGS IDENTIFIED AND TRACKED UNDER THE POLICY | 49 |
| 6.5 CURRENT LIVING ARRANGEMENTS..... | 50 |
| 7. ANALYSIS OF 2016 ACTIVITY: CHALLENGES & SOLUTIONS | 52 |

| | | |
|---|---|-----------|
| 7.1 | ACCOMMODATION CHALLENGES | 52 |
| 7.1.1 | <i>Sourcing Accommodation</i> | 52 |
| 7.1.2 | <i>Lead- in time for HSE Capital Funded projects</i> | 53 |
| 7.1.3 | <i>Accessing Capital Assistance Scheme (CAS) Funding</i> | 54 |
| 7.1.4 | <i>Property Adaptation</i> | 55 |
| 7.1.5 | <i>Impact of Regulation by HIQA</i> | 55 |
| 7.1.6 | <i>Continued Capital Investment in Congregated Settings</i> | 56 |
| 7.1.7 | <i>New Registration</i> | 56 |
| 7.2 | COMMUNICATION CHALLENGES | 57 |
| 7.2.1 | <i>Supporting the Residents and their Families</i> | 57 |
| 7.2.2 | <i>Supporting staff who work in congregated setting</i> | 58 |
| 7.3 | REVENUE FUNDING CHALLENGES | 59 |
| 7.3.1 | <i>Service Reform Fund -Supporting Change through Leaders & Frontline staff</i> | 59 |
| 7.3.2 | <i>On-going Revenue Funding</i> | 60 |
| 8. | PRIORITY ACTIONS AND WORK PLAN FOR 2017 | 66 |
| 8.1 | NATIONAL SERVICE PLAN 2017 AND NATIONAL SOCIAL CARE OPERATIONAL PLAN 2017 | 66 |
| 8.2 | DETAILED ACTIONS RELATING TO “TIME TO MOVE ON” IN 2017 | 67 |
| 9. | ADDRESSING THE CHALLENGES IDENTIFIED IN 2016 | 68 |
| 9.1 | ACCOMMODATION CHALLENGES | 68 |
| 9.2 | COMMUNICATIONS | 69 |
| 9.3 | REVENUE RESOURCE CHALLENGES | 69 |
| 10. | CONCLUSIONS & NEXT STEPS | 70 |
| APPENDIX 1: PROGRESS ON IMPLEMENTING TIME TO MOVE ON FROM CONGREGATED SETTINGS REPORT 72 | | |
| | TABLE A1: CURRENT STATUS OF REPORT RECOMMENDATIONS ON 31/12/16 | 72 |
| | TABLE A2: DETAILED REVIEW OF REPORT RECOMMENDATIONS AND CURRENT STATUS | 73 |
| APPENDIX 2: TIME TO MOVE ON SUBGROUP MEMBERSHIP IN 2016 | | |
| APPENDIX 3: 2015 ADMISSIONS /RE-ADMISSIONS UPDATE | | |
| APPENDIX 4: PROFILE OF CONGREGATED SETTINGS REMAINING AT 31/12/2016 | | |
| APPENDIX 5: DETAILS ABOUT A CONGREGATED SETTINGS THAT CLOSED DURING 2016..... | | |
| | GROVE HOUSE..... | 91 |
| APPENDIX 6: 2017 WORK PLAN ACTIONS..... | | |
| | | 93 |

Introduction

We are pleased to present the 2016 Annual Progress Report for the *Time To Move On From Congregated Settings: A Strategy for Community Inclusion* policy. This report is drafted to provide useful and accessible information relating to the implementation of the policy, including details of the activity, the transitions successfully completed and the challenges faced. This is the second annual report to be submitted for publication since the policy was implemented in 2012. The 2015 report remains available on the HSE's dedicated Time To Move On webpage www.hse.ie/timetomoveon

The report provides an overview of the work being undertaken at a national level to drive the policy implementation and the challenges that are arising for service providers. The 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 2016.

The report highlights that achieving a significant transformation in the residential service model continues to be challenging for both the disability sector and society as a whole. Moving from a traditional centre-based model to a person-centred model of support requires a fundamental shift in the mind set. This can be a challenge the families and the residents themselves as well as for service providers, frontline support staff, government departments, advocacy services, local authorities, local community groups, primary care providers and organisational leaders. It is acknowledged that some families have concerns about the policy and there is a commitment to listening and engaging with families, to ensure the role they have in each person's life is respected.

The information gathered during 2016 demonstrates 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. In 2016, we have seen continued progress as individuals around the country have been supported to experience a positive transition to new homes in the community. The overall number of transitions completed was less than planned, but the additional capital and revenue investment committed during the year led to many transitions being progressed that have been delivered in 2017.

Looking to the future, the data demonstrates that on-going work is needed to build the capacity of service users, their families and service providers, the support of other

stakeholders, along with continued investment in order to sustain this activity.

Finally, from 2017 the development of multi-annual plans and activity targets will ensure that the time-frames set for completing transitions will support meaningful person-centred planning and enable providers to forward plan developments. This will enable service providers to progress each transition in line with the individual's needs and wishes, support meaningful engagement with families as part of the planning process and ensure that there is sufficient lead-in time to address all the changes associated with transitioning.

1. Policy Background and National Context

1.1 Time To Move On From Congregated Settings

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 4000 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. It was envisaged that delivering on the recommended actions could bring about the necessary wide reaching changes to support and drive the implementation of the report findings. This would enable individuals in congregated settings to transition to homes in the community and live meaningful lives of their choice. The recommendations fall into a number of broad categories

- Development of national policy and national strategies to support implementation
- Leadership & Implementation structures
- Key principles to be adopted
- Funding streams and mechanisms
- Managing the reconfiguration of existing services
- Supporting the individual to have a life of their choice and a meaningful day
- Assessing and evaluating change and sharing the learning
- Other areas for consideration

Work is on-going to address all the recommendation in the report, as part of the overall work plan of the *Time To Move On* Subgroup and in collaboration with other stakeholders. In Appendix 1 a full list of the recommendations from the *Time to Move On* report is listed and an update on the status of each recommendation as at 31/12/16 along with a brief commentary is provided.

In 2015 a submission by the HSE Social Care Division to the Department of Health identified that significant capital resources were required to support the delivery of appropriate housing to enable individuals to move. In 2016 the Department of Health committed to a Disability Capital Programme of €100 million dedicated to the provision of accommodation for those individuals moving from congregated settings to homes within the community during the period 2016-2021. This commitment is included in the *2016 Programme for Partnership Government* document that sets a national target for a one third reduction in the number of individuals residing on congregated settings. This would see the number of people remaining in congregated settings fall to 1,819 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). It is a stated aim of Government that the UNCRPD will be ratified in the short term. 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.”*

(UNCRPD, 2006 Article 19)

The *Time To Move On From Congregated Settings* 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

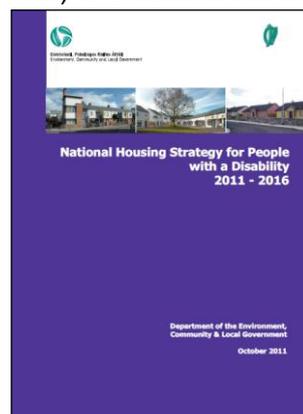
The provision of appropriate accommodation to support people with disabilities is fundamental in order to progress the implementation of the *Time To Move On From Congregated Settings* policy. The need for people with disabilities to have access to appropriate affordable accommodation has been supported by housing policy and key strategies introduced by the Government. There are currently three key policy documents which inform the national approach to the delivery of housing for people with disabilities in the community:

- *National Housing Strategy for People with a Disability 2011-2016*, Department of the Environment, Community and Local Government, 2011
- *Social Housing Strategy 2020: Support, Supply, Reform* Department of the Environment, Community and Local Government, 2014 – 2020
- *Rebuilding Ireland Action Plan on Housing and Homelessness* Department of the Housing, Planning, Community and Local Government 2016.

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”.



Previously many people with disabilities had their housing needs met through health-funded service providers. Under this strategy people with disabilities will have access to social housing through Local Authorities in the same way as all citizens do.

The Strategy sets out an integrated approach to the provision of housing and support services from the Local Authorities and the HSE that will enable people with a disability to live the life of their choosing in their own homes, in accommodation that is designed and/or adapted as necessary to meet their needs.

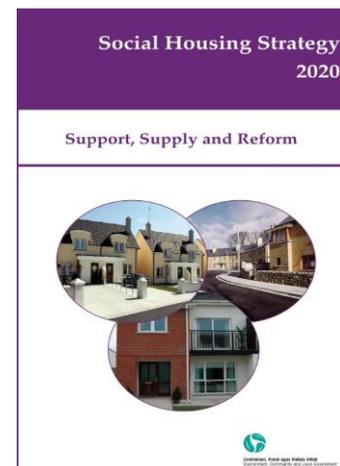
A Programme for a Partnership Government (2016) commits to meeting the housing needs of people with a disability, and the NHSPwD has been affirmed in *Rebuilding Ireland (2016)* and extended to 2020 to continue to deliver on its aims.

Implementation of the NHSPwD is also a key commitment under the Government's *National Disability Strategy Implementation Plan (NDSIP)* which was published in July 2013 and will also be reflected in the new National Disability Strategy Implementation Plan 2017-2019. The NHSPwD supports the NDSIP's high level objectives that people with disabilities should be supported to live ordinary lives in ordinary places, participating in the life of the community.

1.3.2 Social Housing Strategy 2020

The Department of the Environment, Community and Local Government (DECLG) developed and launched a six year *Social Housing Strategy* in 2014. 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 Government* contains a commitment to incorporate the needs of people with disability into all future housing policies.

1.3.3 Rebuilding Ireland 2016

The Department of Housing, Planning, Community and Local Government (DHPCLG) launched its five-year action plan for housing and homelessness in July 2016. The overarching aim of this Action Plan is:

- To ramp up delivery of housing from its current under-supply across all tenures to help individuals and families meet their housing needs, and
- To help those who are currently housed to remain in their homes or be provided with appropriate options of alternative accommodation, especially those families in emergency accommodation.



The plan has a number of specific actions relating to housing for people with a disability. The Department will:

- Increase the target of the Housing Adaptation Grant drawdown to 10,000 homes in 2017 (up from 8,000 in 2016) and streamline the application process
- Work with the HSE and local authorities on all issues, including funding supports, for housing people who are transitioning from HSE accommodation and for clients of the mental health services living in community-based accommodation
- Continue to support the Department of Health and HSE in the programme of transitioning people from congregated settings to community-based living through ring-fenced housing capital funding
- Extend the NHSPwD beyond its timeframe of 2016 to continue delivery on its aims.

2. Current Structures Supporting the Implementation of the Policy

There are a number of structures and groups who have a focus on the implementation of the *Time To Move On From Congregated Settings* policy as part of their work. The current role and activity of each of these groups in relation to policy implementation is outlined below.

2.1 *Time To Move On Subgroup under the Transforming Lives Programme*

The Transforming Lives Programme is the reform programme that is driving the implementation of the recommendations of the Department of Health's 2012 *Value for Money and Policy Review* report as well as national policies that will deliver person-centered models of service. The Programme will ensure that people with disabilities are supported to make the type of 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 includes the implementation of the *Time To Move On From Congregated Settings* 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)*.

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 2016 Subgroup members please refer to Appendix 2.



As part of the Transforming Lives Programme a work plan is in place for the Subgroup to ensure there is a focus on completing defined deliverable actions. This work plan is periodically reviewed to ensure that it continues to be aligned with and supports the delivery of targets set out in Government priorities, HSE National Service Plan and the National Operational Plan for the Social Care Division. The work plan is also monitored as part of the HSE's overall System Reform Programme.

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. During 2016 the *Time To Move On* Subgroup worked particularly closely with the Transforming Lives Working Group 1 Subgroup and the National Disability Authority (NDA) on the development of an Individual Outcome Assessment Tool. This tool will be administered pre and post transition with those individuals moving to new models of service in the community in order to assess the impact and outcome of the change on individuals. The first phase of this work, which is called the "Moving Out" project, commenced in 2016 by the team of trained interviewers carrying out the assessments with individuals under the direction of the NDA team.

2.2 National Housing Strategy for People with Disability Subgroup

A multi-stakeholder group was established in 2012 to support the uniform implementation at a local level of the recommendations of the *National Housing Strategy for People with Disability 2011 – 2016 (NHSPwD)*. The role of the Sub-group is to:

- Support the effective implementation of the *National Housing Strategy for People with a Disability 2011 – 2016*
- Facilitate a uniformity of approach in the implementation of housing policy for people with a disability at local level
- Agree and implement a prioritised work programme to progress housing-related priority actions listed in the NHSPwD National Implementation Framework
- Develop and provide guidance to housing authorities on issues relating to housing for people with a disability, document and share good practice and clarify the role of the various stakeholders
- Progress the housing provisions set out in the Government's Mental Health Policy, *A Vision for Change* and the report of the Working Group on Congregated Settings, *A Strategy for Community Inclusion – Time To Move On From Congregated Settings*.

- The Subgroup will report and liaise, as appropriate, with the Congregated Settings National Implementation Project Team (now the *Time To Move On* Subgroup under the Transforming Lives programme), in relation to the housing elements of *Time To Move On From Congregated Settings: A Strategy for Community Inclusion*.
- Liaise and work with the Implementation Monitoring Group (IMG) in relation to the development of appropriate guidance for housing authorities and report progress on a regular basis.

This group, led and chaired by the Housing Agency, met regularly in 2016 to progress the strategic aims within the NHSPwD 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 work of the group is not exclusively focussed on those residents that are being supported to move from congregated settings, but they are a priority group as recognised in the Strategy (NHSPwD) and much of the work of the group is relevant to and will benefit residents from congregated settings.

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 DHPCLG 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 From Congregated Settings*.

2.3 HSE Estates & Disability Oversight Group

A national HSE Estates and Disability Oversight Group was established in 2016 to ensure that a collaborative and co-ordinated approach was taken with regard to the multi-annual Disability Capital Programme 2016-2021. The group is made up of staff from HSE Estates (who have responsibility for Capital projects) and members of the HSE Disability Reform and Operations Teams implementing the *Time To Move On From Congregated Settings* policy nationally. The Group work to:

- Oversee the roll-out of the disability capital programme for congregated settings nationally

- Liaise with relevant Government Departments in the provision of Social Housing
- Prepare multi-annual programme for the roll-out of the disability capital programme
- Liaise with and provide training to all local CHO and Estates offices ensuring consistent delivery nationally
- Monitor and report on programme progress at regular intervals (quarterly)
- Develop appropriate accommodation standards, licences, leases
- Consider all new capital project submissions and make recommendation to HSE National Property & Capital Steering Group.

The specific work that the group undertook and delivered in 2016 is detailed later in this report under Section 4.2 *Process, Oversight & Support of Capital Programme in 2016*.

2.4 HSE Disability Team Oversight Group

In 2016 it was recognised that intervention was needed at a national level, to support the “priority site” congregated settings to develop robust project action plans and funding proposals. The priority sites are those identified specifically for accelerated decongregation, due to significant concerns around compliance with the National Disability Residential Standards as regulated by HIQA. A group was formed with members drawn from the National Disability Reform and Operations Team who have expertise in relation to policy, quality improvement, financial feasibility and local knowledge. Coming together under the chair of the Transforming Lives Programme Manager, the group had oversight of the development of the plans and proposals and were able to provide collated feedback, support and guidance to the providers and CHO teams. This ensured that gaps and deficits in the plans could be addressed at an early stage and engagement with services could focus on supporting providers to address these issues. The process also helped to identify good practise and ensure that providers making progress could be supported and encouraged to share their learning and mentor other teams.

Alongside the individual reports and feedback provided to teams, there was also a national feedback report developed that identified the key themes emerging from the planning process. This identified a number of challenges and learning points that informed the engagement with service providers and the supports put in place to drive policy implementation later in 2016 and into 2017.

3. Work Undertaken to Drive Policy Implementation During 2016

3.1 “Time to Move On” Implementation Framework

The Implementation Framework that was under development in 2015 was progressed and re-focused in 2016, to bring together resources that have been specifically developed to guide providers and other stakeholders as they work to support individuals to move from congregated settings. The Framework is currently made up of a suite of stand-alone guidance documents referred to as *resources*. Each resource examines a specific topic under one of the nine key themes that are identified as priority work strands for organisations implementing the *Time To Move On From Congregated Settings* policy.

During 2016 a number of new resources were completed and added to the Framework which now includes the following resources:

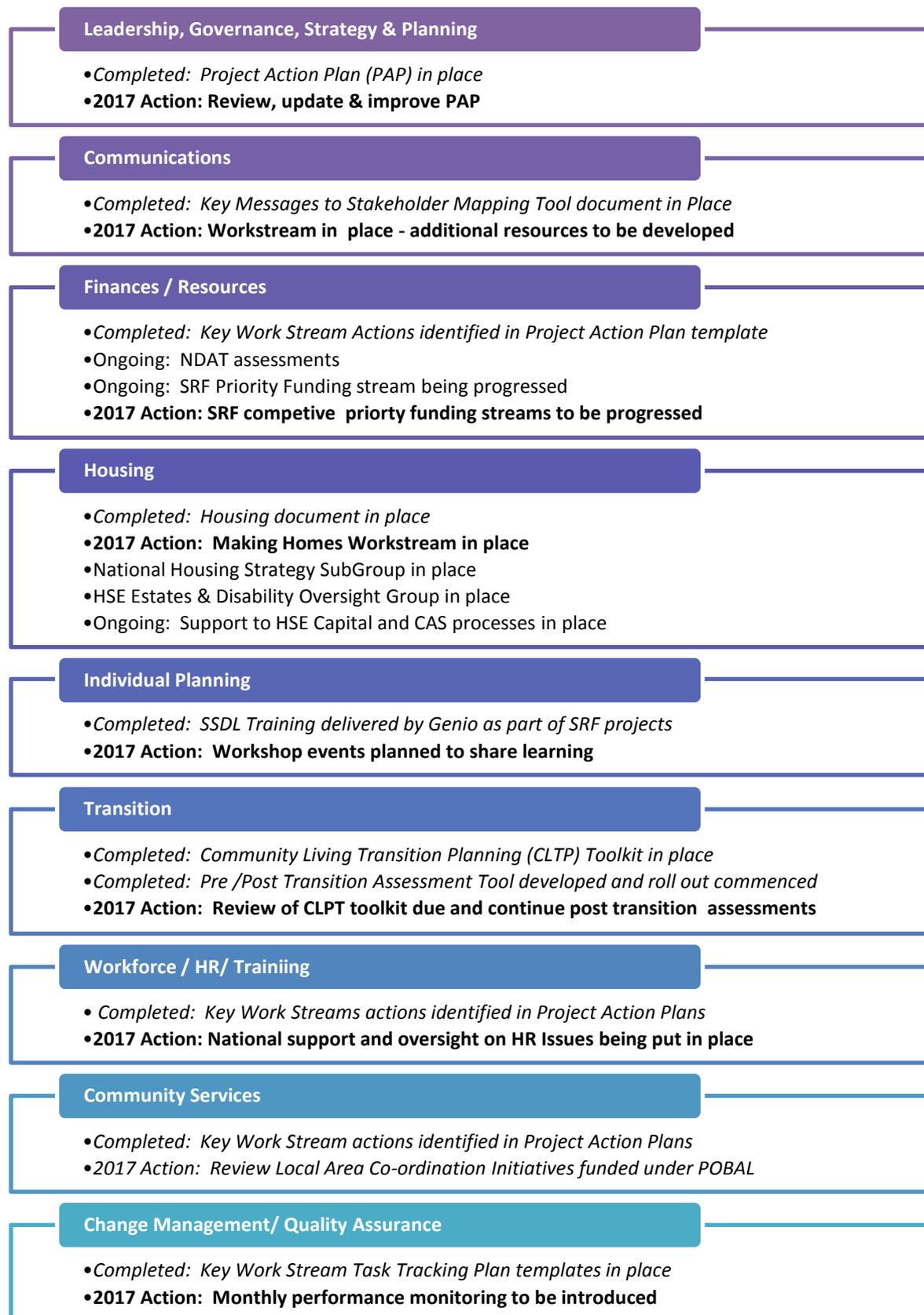
- Project Action Plan Tool
- Communication Plan- Key Messages and Stakeholder Mapping Tool
- Community Living Transition Planning Toolkit
- Housing Options Resource Document

Further details of the new resources added to the Framework in 2016 are given in *Section 3.3 New Resource Documents*. The Framework is also supported by a number of on-going processes:

- HSE Disability Capital Funding Programme
- DECLG Capital Assistance Scheme
- Service Reform Funding
- HSE & Disability Estates Oversight Group
- National Housing Strategy for People with Disabilities Steering Subgroup
- Pre & Post Transition Outcome Assessments under the “Moving Out” project.

In Chart 1, the support structures and resources already in place as part of the Implementation Framework are mapped against the nine key themes. The chart also shows the resources and structures that are due to be developed and introduced in 2017.

Chart 1: Implementation Framework



The resources are not prescriptive “how to” guides, as organisations are encouraged to only adopt the elements and approaches that are appropriate to their service, which will be dependent on the nature of the service, the progress made to date and the organisational ethos and configuration.

3.2 Supporting the Policy

The work undertaken in 2016 to support the implementation of the policy included:

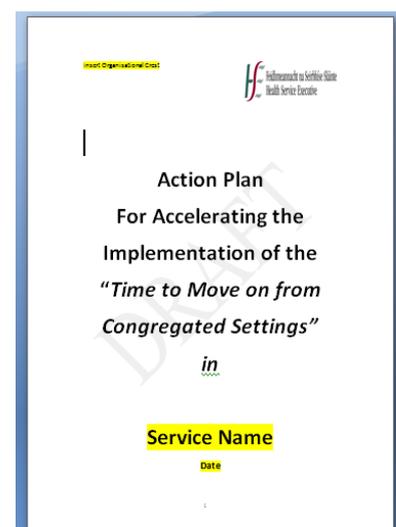
- The development of a suite of resource documents to support service providers to implement policy (as part of the Implementation Framework),
- The development and management of an enhanced tracking tool and information set to enable accurate and timely oversight of activity that is in line with policy at a national level,
- The delivery of a range of additional initiatives including stakeholder engagements at both national and local level structured workshops

3.3 New Resource Documents

3.3.1 Provider Action Plans

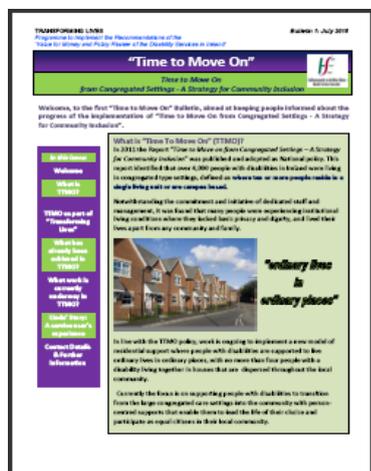
At the start of 2016, a suite of documentation to guide and support priority sites to develop their Action Plans for the transitioning of individuals from congregated settings was developed and disseminated to service providers and CHO teams. This resource focused on:

- Supporting service providers to deliver a plan that can be implemented and used as an on-going project management tool to track and manage project progress
- Informing and guiding organisations on the key work streams required as part of a change project to successfully support people moving to the community
- Supporting providers with the reconfiguration of resources and enable the identification of transitional resource requirements
- Supporting providers to develop plans for part of a service or a group of individuals in the context of operating a larger congregated setting.



The Communication Strategy was finalised, approved and published during 2016 and can be accessed on the webpage www.hse.ie/timetomoveon/

3.3.3 National “Time To Move On” Bulletin



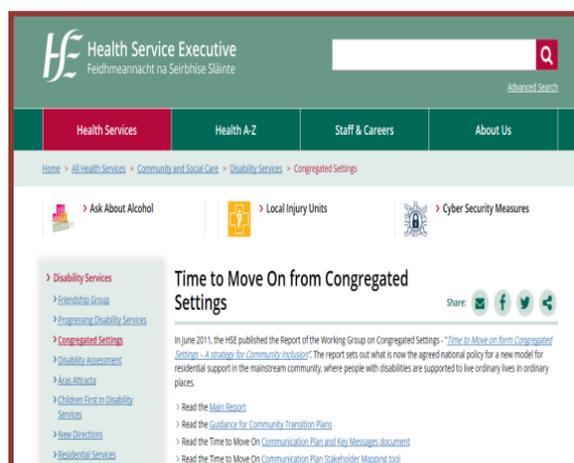
The first bulletin on the progress of the policy was released in July 2016.

This was developed for a broad audience including families, frontline staff and members of the public to provide an overview on the policy, to signpost a number of current developments and information sources and to tell the personal story of a service user who has moved into the community, from their viewpoint.

3.3.4 National Time to Move On Webpage and contact address

The HSE’s webpage on *Time To Move On From Congregated Settings* was updated in July 2016. The page address is www.hse.ie/timetomoveon

The communication documents, action plans templates, toolkits and bulletin can now be viewed and downloaded from the webpage. As additional resources are created these are uploaded to the page. The 2015 Progress Report on Policy Implementation is also available on this page.

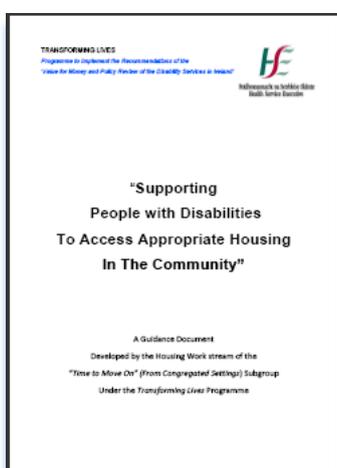


A generic email address was also created timetomoveon@hse.ie, to facilitate members of the public and other interested parties to make direct contact with the *Time To Move On* team leading on the policy.

3.3.5 Supporting People with Disabilities To Access Appropriate Housing In The Community” Housing Guidance Document

A comprehensive guidance document was drafted in 2016 to signpost for providers how they can support people with disabilities to access appropriate housing in line with the *Time To Move On From Congregated Setting* policy.

The document starts by focussing on the good practice approaches that are recommended for providers to ensure people with disabilities are supported to determine their will and preference around their future homes.



Within the guidance document all the funding mechanism options available to support the provision of social housing are identified. Concise details are given on the eligibility criteria, application processes and the specific funding arrangements that relate to each option along with clarity as to the responsible body and the key partners in each case. Links and references are provided to the documentation available elsewhere on the specific schemes, which enables providers to examine potentially relevant options in greater detail, contact relevant partners and pursue appropriate options.

3.4 Enhanced Quarterly Performance Tracking

During 2016 further amendments were made to the quarterly tracking templates, which ensured there was greater accuracy in the tracking of movements within congregated settings. This reduced the incidence of reporting errors and improved national oversight, on a quarterly basis, particularly in relation to the types of transitions achieved and where other movements including transfers between services and admissions occurred.

Aside from the development of resource documents a number of specific activities and initiatives were also undertaken to drive forward policy implementation.

| Category | Q1 | Q2 | Q3 | Q4 | Total | Notes |
|--------------|-----------|-----------|-----------|-----------|------------|-------|
| Admissions | 10 | 12 | 15 | 18 | 55 | |
| Transfers | 5 | 8 | 10 | 12 | 35 | |
| Discharges | 8 | 10 | 12 | 15 | 45 | |
| Deaths | 2 | 3 | 4 | 5 | 14 | |
| Other | 1 | 2 | 3 | 4 | 10 | |
| Total | 26 | 35 | 42 | 54 | 157 | |
| Admissions | 10 | 12 | 15 | 18 | 55 | |
| Transfers | 5 | 8 | 10 | 12 | 35 | |
| Discharges | 8 | 10 | 12 | 15 | 45 | |
| Deaths | 2 | 3 | 4 | 5 | 14 | |
| Other | 1 | 2 | 3 | 4 | 10 | |
| Total | 26 | 35 | 42 | 54 | 157 | |

3.5 Master Data Set validation 2016

The Master Data Set is designed to capture key information in relation to each person who is or has been a resident in a congregated setting at any point since the policy was implemented in 2012. 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, who update the information on all individuals periodically.

The MDS when validated with the quarterly performance tracking templates provides robust and detailed information that is used to generate the Annual Progress Report and can be used to provide useful statistical information on a geographical basis, by Community Health Organisation and by individual agency. An update and validation of the MDS was completed twice in 2016 to capture key information on the changes in the circumstances of all those living in a congregated settings. The information gathered in 2016 is presented later in this report under *Section 5: Population remaining in Congregated Settings*.

3.6 Service Provider Learning Events & Initiatives

During 2016 three workshops were held that focused on specific themes and work areas. These workshops were targeted primarily at the priority sites and HSE Community Health Organisations (CHOs), but all congregated settings Service Providers were invited to attend and participate. An outline of the focus of each of the three workshops held is given below. After each event, copies of the presentations delivered by the speakers were circulated by email to those who attended on the day. These remain available for circulation and can be accessed by sending an email request to timetomoveon@hse.ie with details of the presentation required.

February 2016:

THEME: Planning for the implementation of the policy in a setting.

This event was targeted at the new CHO teams and all priority sites for decongregation. Four keynote speakers delivered presentations on the following topics and participated in a robust Q & A session on:

- The Status of policy implementation and next steps for priority sites
- New Disability Capital Programme and HSE processes
- Change Management & Project Management processes

- Project Action Plans – Introduction and Overview
- Service Reform Fund Overview.

Following the workshop all priority providers were required to develop and submit project action plans within a defined period.

June 2016:

THEME: Housing Options & Funding Mechanisms

This event was targeted at CHO Disability Managers, Senior Managers from the Service Providers and representatives from the Approved Housing Bodies. The overall focus of the day was to examine the role of the various stakeholders in meeting the housing needs of people transitioning from congregated settings. Supporting individuals to determine their housing preferences was also discussed. Eight speakers delivered presentations on the following topics and participated in Q & A sessions:

- Overview & Launch of the Guidance Document on meeting the housing needs of people with disabilities
- Two Service User Stories -Their lived experience of moving from a congregated setting to their own home
- Service Provider Story-Their experience of supporting individuals to find a home of their choice
- Overview of the work on-going under the National Housing Strategy for People with Disabilities
- Overview of Social Housing Supports, Housing Schemes & Funding Mechanisms.
- Focus on the Capital Assistance Scheme processes 2016
- Approved Housing Bodies Stories- Examples of recent and on-going collaborative projects to support people with disabilities.

The day also included a session to facilitate Approved Housing Bodies and Service Providers to network and forge contacts to encourage future collaboration on housing projects for people with disabilities.

Following the workshop all providers were required to develop and submit a housing assessment profiling template within a defined period that would inform the multi-annual housing profile being developed.

November 2016:

THEME: Communication, Advocacy and Transitions in practise

This event was targeted at the CHO Disability Managers and senior managers from all the congregated settings. The overall focus of the day was to formally launch the Communication Plan, to highlight the role of the National Advocacy Service and to hear from Service Providers who have completed the transition of individuals from congregated setting. Six speakers delivered presentations on the following topics and participated in Q & A sessions:

- Launch and overview of the Communication plan
- Service Provider Presentation - lived experience of communication to support decongregation and learning from this
- The role of the National Advocacy Service
- Planning for transitions – the process of planning and managing change
- Two Service Provider Presentations - Exploring the lived experiences of planning for the transition process in specific services and how this works in practise.

3.7 Centre Visits

In 2016, the programme of site visits by the Project Lead and Project Support Officer and other members of the *Time To Move On* Subgroup continued. This provided an opportunity to:

- Highlight the work being done at a national level to support the implementation of *Time To Move On From Congregated Settings* and to engage with the providers to promote the implementation of the policy in their service.
- Improve communication and networking between local Service Providers and national teams and building commitment at a local level to implement the policy.
- Share learning and target future activity. Providers were able to highlight specific areas where targeted additional support would assist in addressing issues that impact their capacity to implement the policy locally. The team were also able to link with providers who have experience of transitioning and are developed expertise and knowledge that could be shared.
- Enable the team to develop a much greater understanding of the configuration of services that exist within individual organisations and the support needs and circumstances of the residents these providers support. In some cases it also provided the opportunity to clarify the status of particular settings under the *Time To Move On From Congregated Settings* policy.

During 2016, the following centres facilitated members of the Subgroup with on-site visits:

- COPE Foundation, Ashville Centre, Cork
- Stewarts Care, Palmerstown, Dublin
- Peamount Healthcare, Co Dublin
- Brothers of Charity Southern Services, Upton Campus, Cork
- St Michaels House, The Glens , Ballymun, Dublin
- HSE St Joseph's IDS, Portrane
- Daughters of Charity St Rosalie's, Portmarnock
- HSE St Raphael's Centre, Youghal
- Brothers of Charity, Bawnmore, Limerick
- Daughters of Charity, St. Vincent's Centre, Lisnagry
- Daughters of Charity, St. Vincent's Centre, Dublin

4. Capital Funding

4.1 HSE Disability Capital Funding Programme in 2016

The HSE made a submission to the Department of Health in June 2015, outlining a proposal to accelerate the implementation of the *Value for Money and Policy Review* and *Time To Move On From Congregated Settings* Reports. This submission outlined that four strands of work were required to implement the policy for all people living in congregated settings.

Strand 1 focused on the large institutional congregated settings which had been the subject of significant concerns in HIQA inspections, over recent months, with significant non-compliance with HIQA standards.

In 2016 the Department of Health announced dedicated HSE capital funding of €100m allocated for disability services over the period 2016–2021. This funding is to be targeted to increase the pace of plans of a new model for residential support in the community, in line with the HSE's *Time To Move On From Congregated Settings* policy. In 2016, €20 million of the dedicated capital funding was made available and allocated to the 14 congregated centres that were prioritised nationally for capital investment. The 14 centres supported were those identified under Strand 1 in the 2015 submission, with some slight amendments to reflect changes that occurred in the 12 months since the submission was drafted.

This funding was targeted to enable these 14 centres to support the transition of at least 165 individuals to appropriate community-based accommodation where person centred models of service can be delivered. The investment also ensured that there would be a reduction in the resident numbers remaining in the large congregated settings. This in turn would support these services to be reconfigured to improve the standard and safety of care for those remaining in these settings and improve and level of HIQA compliance to the greatest degree possible.

The 14 centres that received funding and the number of residents targeted for transition with this investment are detailed over.

| Sites Prioritised for Capital Funding in 2016 | | |
|--|---|--|
| Area | Site | Number of Residents to transition |
| CHO 1 | HSE Sligo, Cregg House | 17 |
| CHO 2 | HSE, Aras Attracta | 20 |
| CHO 2 | Brothers of Charity Galway, John Paul Centre | 4 |
| CHO 3 | Daughters of Charity, Lisnagry | 8 |
| CHO 3 | Daughters of Charity, Roscrea | 14 |
| CHO 4 | HSE, Cluan Fhionnáin Kerry | 12 |
| CHO 4 | HSE St. Raphael's, Main Centre, Youghal | 22 |
| CHO 4 | St. John of God, Beaufort Campus , Co Kerry | 4 |
| CHO 4 | COPE Foundation, Ashville | 8 |
| CHO 5 | St. Patrick's Centre, Kilkenny | 16 |
| CHO 6 | HSE Southside ID Service, Good Counsel Centre | 4 |
| CHO 7 | St. John of God, St Raphael's Centre, Celbridge | 8 |
| CHO 8 | St. John of God, St Mary's Campus ,Co Louth | 20 |
| CHO 9 | Daughters of Charity, St Rosalie's, Portmarnock | 8 |

4.2 Process, Oversight & Support of Capital Programme in 2016

As noted previously, a National HSE Estates and Disability Oversight Group was established in 2016 to ensure that a collaborative and co-ordinated approach was taken with regard to the multi-annual Disability Capital Programme 2016-2021. In order to enable and support the delivery of housing in the priority sites the group:

- Met quarterly to monitor and track project progress ensuring that concerns around project viability, appropriateness, value for money etc. would be identified and addressed
- Engaged with all CHO and local HSE Estates offices to develop a consistent approach to the delivery of housing nationally
- Liaised with relevant government departments (DOH/ DHPCLG) and other authorities and bodies (NDA, HIQA) to ensure the development of housing solutions aligned to social housing policy, reflecting current good practise in terms of design and meeting regulatory and statutory requirements (i.e. Fire & Building regulations, National Residential Standards regulated by HIQA).

- Commenced working on the preparation of a multi-annual plan to support the delivery of the Disability Capital Programme.
- Commenced work on the development of guidelines/specifications to support HSE Estates and service providers in sourcing appropriate housing.
- Began work on drafting of accommodation standards, licences, leases.
- Established a review process for all new capital project submissions and for the making of recommendations to the HSE National Property & Capital Steering Group.

4.3 Capital Assistance Scheme Guidelines (CAS)

The Department of Housing, Planning, Community and Local Government (DHPCLG) Housing Circular 45/2015 was introduced in November 2015. This circular sets out the specific requirements that projects funded under the Capital Assistance Scheme must satisfy. These requirements are focused on ensuring that housing for people with disabilities provided under CAS will support people moving from congregated settings to community living, in line with the *Time To Move On From Congregated Settings* policy.

Circular 45/2015 confirmed that the use of HIQA “designated centre” status could no longer be used as a criteria to exclude properties from CAS funding. It also states that the person/tenant must have capacity to sign a meaningful Tenancy Agreement, or pending the enactment of the Assisted Decision Making (Capacity) legislation, confirmation must be provided by the service provider that the tenant(s) will be supported to live self-directed lives with meaningful choice, free from routines that would normally apply in a congregated or residential group setting.

During 2016, the HSE worked closely with the DHPCLG prior to the release of Housing Circular 29/2016, known as the “CAS call”. This circular identified the application process for housing projects under the Scheme. Circular 29/2016 confirmed that funding was being made available in 2016 specifically to support those transitioning from congregated settings (in line with Circular 45/2015 as detailed above and in line with HSE policy)

4.3.1 Potential Projects identified for CAS Funding

The HSE’s submission to the Department of Health in June 2015 outlined a proposal to accelerate the implementation of the *Value for Money and Policy Review* and *Time To Move On From Congregated Settings* Reports, with four strands of work identified to implement the policy for all people living in congregated settings.

Strand 2 focused on a proposal developed by the *Time To Move On* Subgroup to target individuals who can be supported in community living, if appropriate housing accommodation is provided and/or funded under DHCLG arrangements (i.e. CAS, CALF, leasing, social housing) or other housing schemes. Under the 2016 Capital Assistance Scheme Call funding was made available for many projects identified under Strand 2.

4.4 Service Reform Fund 2016

The Service Reform Fund (SRF) was established to support the implementation of reforms in the Disability and Mental Health Services by providing funding to meet the costs of migrating to a person-centered model of services and supports, in line with the Government's stated policies. 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-centered model of services and support
- Developing capability
- Research and Evaluation
- Supporting the development of an advocacy framework.

The implementation plan for the SRF identified the following priorities in Disability Services:

- Supporting approximately 150 people per year to transfer to community living from the ten priority congregated sites. This includes the provision of day services in line with the New Directions model of service
- Open competitive funding across two streams i.e. moving from institutional living to community living and person centered model of day service.

4.4.1 Service Reform Fund Priority Sites

In line with the National Service Plan the 2016 Social Care National Operational Plan recognised the need for an accelerated implementation of the *Time To Move On From Congregated Settings* policy. This followed the submission to the Department of Health in 2015 in which priority sites were identified where there was a major concern about compliance with HIQA regulation and basic standards of care.

The 2016 Social Care Plan prioritised 10 sites for a ring-fenced funding stream in order to

promote and support these services to achieve the targeted levels of transitions identified. These Service Providers were also being supported with capital funding in relation to the acquisition of homes for the people who are targeted to transition.

In 2016 work was undertaken on establishing criteria for inclusion in the SRF and capacity building will enable proposals for funding in future years to be identified by the end of the first quarter 2017.

5. Population Remaining in Congregated Settings

The National Service Plan 2016 prioritised the implementation of the *Time To Move On From Congregated Settings* policy with a plan to complete the transition of 160 people by the end of 2016. In total 74 individuals completed their transition to the community during the year and a further 87 individuals were identified as being actively engaged in the process of transition planning at the year end. The challenges arising and the time required to support the overall transition process are explored in more detail in *Section 6 - Analysis of 2016 Activity: Challenges & Solutions*.

At the end of 2016 there were 2,579 people who remained resident in congregated settings. The overall drop in the population that remained within the congregated settings was 136 people in 2016. This figure includes transitions as well as all other movements including deaths, emergency admissions, other discharges and transfers.

The key findings from an analysis of the information on movements during 2016 are presented below in Table 1:

| Table 1: Movement of People in Congregated settings during 2016 | | |
|--|-------------------------|------------------------------|
| Type of movement | Number of People | % of Total population |
| People living in a cong. setting on 01/01/16 | 2,715 * | n/a |
| Transitions completed | | |
| A. People who moved to homes in the community in line with the policy | 49 | 1.8% |
| B. People who transitioned to other appropriate arrangements | 25 | 0.9% |
| All transitions completed at A & B above | 74 | 2.7% |
| Other movements | | |
| People admitted / readmitted in year | 34 | 1.3% |
| Individuals who passed away in 2016 | 96 | 3.5% |
| People living in a cong. setting on 31/12/16 | 2,579 | 5% Decrease |

* Following a validation of the 2015 Annual report Figure the 2016 starting figure was decreased by 2

5.1 Transitions in 2016

Further data analysis has been carried out to look at the profile of the individuals that were supported to transition during 2016 and to examine various aspects of the post transition arrangements, including accommodation type, staffing, funding and living arrangements.

Table 2 identifies the number of people that were supported to move during 2016, broken down into age groups. It shows that 28.4% of the people that moved were aged 50 to 59 years of age and the average age of a person that transitioned was 48 years. The oldest person was 82 years of age and the youngest person was 10 years of age.

| Age Category | No. of People | % of those that transitioned |
|-----------------------|----------------------|-------------------------------------|
| Under 18 years of age | 5 | 6.8% |
| Aged 18 to 29 years | 3 | 4.1% |
| Aged 30 to 39 years | 13 | 17.6% |
| Aged 40 to 49 years | 13 | 17.6% |
| Aged 50 to 59 years | 21 | 28.4% |
| Aged 60 to 69 years | 13 | 17.6% |
| Aged 70 to 79 years | 4 | 5.4% |
| Aged over 80 years | 2 | 2.7% |
| | 74 | 100.0% |

Five young people under the age of 18 transitioned in 2016. These young people were all admitted in 2015 and spent less than one year in a congregated setting. One has a moderate degree of disability and 4 have a severe disability. All 5 young people required high or intensive levels of support.

Table 3 identifies the primary disability of the people that were supported to move during 2016. It shows that 30 people with a moderate ID were supported to move, making this the most targeted group, accounting for 40.5% of all those that transitioned. 20 people (27%) with a severe level of disability transitioned and a further 10 individuals (13.5%) with a primary physical & sensory disability transitioned.

| Table 3: Level of Disability of the People that Transitioned in 2016 | | |
|---|----------------------|-------------------------------------|
| Primary Disability Identified | No. of People | % of those that transitioned |
| Mild | 9 | 12.2% |
| Moderate | 30 | 40.5% |
| Severe | 20 | 27.0% |
| Profound | 4 | 5.4% |
| Physical & Sensory | 10 | 13.5% |
| Not known | 1 | 1.4% |
| Total | 74 | 100.0% |

Table 4 gives the support needs identified for all those that transitioned. Looking at the *Level of Disability* (Table 3) and the *Level of Support Needs* (Table 4) together, of the 30 residents with a moderate level of disability that transitioned, there is a clear correlation between the level of disability and the support needs identified with 15 people identified as requiring a moderate levels of support and 10 having a high level of support needs. Similarly, of the 20 residents with a severe level of disability, 17 require a high level of support.

| Table 4: Level of Support Needs of the People that Transitioned in 2016 | | |
|--|----------------------|-------------------------------------|
| Support Needs Identified | No. of People | % of those that transitioned |
| Minimal | 2 | 2.7% |
| Low | 5 | 6.8% |
| Moderate | 20 | 27.0% |
| High | 38 | 51.4% |
| Intensive | 8 | 10.8% |
| Not Known | 1 | 1.4% |
| Total | 74 | 100.0% |

In addition to identifying the level of support needs, service providers also indicated that 30 out of the 74 individuals who transitioned required support for behaviours that challenge, although in only 13 cases was the level of support need identified as being high or intensive.

Table 5 identifies the length of time individuals had lived within a congregated setting prior to their transition. The longest period an individual who transitioned in 2016 had lived in congregated settings was for over 49 years, whilst the shortest period recorded was less than one year. Of the individuals that transitioned the most populated category in terms of the length of stay was for periods of between 21 - 30 years which applied in 15 cases. Looking at all the individuals that transitioned in 2016 where a specific admission date was provided, it was possible to calculate that the average length of stay was 26 years in a congregated setting.

| Table 5: Length of Stay in Congregated setting prior to transition | | |
|---|----------------------|-------------------------------------|
| Length of Stay as at 1/1/2016 | No. of People | % of those that transitioned |
| Less than a year | 10 | 13.5% |
| 1 - 4 years | 4 | 5.4% |
| 5 -10 years | 11 | 14.9% |
| 11 - 20 years | 12 | 16.2% |
| 21 - 30 years | 15 | 20.3% |
| 31 - 40 years | 11 | 14.9% |
| 41 - 50 years | 6 | 8.1% |
| Over 50 years | 0 | 0.0% |
| Not specified | 5 | 6.8% |
| Total | 74 | 100.0% |

Table 6 identifies the housing solution used to support the people that transitioned during 2016. In 2015 the most frequently identified solution was to access housing through private rental arrangements without Rent Supplement, which is identified in 32 cases. In 2016 the most frequent arrangement was through new community homes for 26 individuals a further 12 through private rental arrangements and 9 housing solutions provided through

voluntary housing bodies. This change in the type of arrangements sourced in 2016 reflects that there is now a change in the funding options available for housing to support people with disabilities to move into the community. It also demonstrates that sourcing accommodation through mainstream housing options is becoming less frequent, which can be attributed to: better opportunities now being available through HSE and DHPCLG schemes; overall lack of availability of suitable mainstream social housing options; and competition in the private rental market .

The lack of security for tenants in the private rental market is also driving up the preference for housing through the dedicated funding streams, where people with disabilities will have a long-term secure home.

| Table 6: Housing Solution for those that completed transition process | | |
|--|----------------------|-------------------------------------|
| Type of Housing Arrangement | No. of People | % of those that transitioned |
| Private Rental <u>without</u> Rent Supplement | 11 | 14.9% |
| Nursing Home | 10 | 13.5% |
| Through Voluntary Housing Body | 9 | 12.2% |
| New Community Home | 26 | 35.1% |
| Social Leasing (RAS) | 4 | 5.4% |
| Social Leasing (Leased) | 1 | 1.4% |
| Private Rental <u>with</u> Rent Supplement | 1 | 1.4% |
| Existing Community House | 1 | 4.1% |
| Family Home | 1 | 2.7% |
| Other & Not Specified | 7 | 9.5% |
| Subtotal | 74 | 100.0% |

Tables 7 and 8 identify the new living arrangements in place for the people that transitioned during 2016.

| Table 7: Number of other residents with whom individuals now share a home (where arrangement is in line with the policy) | | |
|---|----------------------|-------------------------------------|
| Type of Living Arrangement | No. of People | % of those that transitioned |
| Person is living alone | 10 | 13.5% |
| Sharing with one other person | 4 | 5.4% |
| Sharing with two other people | 12 | 16.2% |
| Sharing with three other people | 21 | 28.4% |
| Family | 2 | 2.7% |
| Subtotal | 49 | 66.2% |

Table 7 shows that of the 74 people that transitioned, 49 people (66.2%) of those that moved out of a congregated setting now live in arrangements that are in line with the policy, sharing with family members or up to three other people with a disability. There are 21 people (over 28%) now sharing with three other people, 10 people (13.5%) now live alone and 2 people went to live with family members.

It must be acknowledged that in response to particular support needs a range of alternative appropriate arrangements have also been put in place to support people transitioning from a congregated setting. In 2016, particular attention was paid to monitoring activity in this area, to ensure that there was oversight of all alternate arrangements.

Table 8 shows the arrangements to which the other 25 individuals transitioned, that are not strictly in line with the policy. These are transitions where residents were supported to move in line with their person-centred plan to arrangements that offer an appropriate model of accommodation and support. These include over 10 individuals who moved to community group homes that currently fall outside the congregated settings policy as the houses have less than 10 residents, but exceed the threshold of no more than 4 residents set down for new services. Of the 10 people, one person moved to a vacancy in an existing community group home, but the remaining nine people moved to new developments. This arose when individuals transitioning into the care of private providers, who set up homes for more than four people. These homes accommodated those coming from the congregated settings and in some cases other individuals moving into residential services.

There were also 10 people that transferred to mainstream nursing homes, reflecting that as

people with disability age, in some cases the need for support with elder-care needs can become the priority for some individuals. A much smaller number of people transferred to specialist nursing home type units, which is captured under the “Other & Not Specified” category in Table 8.

| Table 8: Number of other residents with whom individuals now share a home not in line with the policy | | |
|--|----------------------|-------------------------------------|
| Type of Living Arrangement | No. of People | % of those that transitioned |
| Existing Group Home with up to 8 others | 1 | 1.4% |
| New Group Home with more than 3 others | 9 | 12.2% |
| Transitioned to a Nursing Home | 10 | 13.5% |
| Other & Not Specified | 5 | 6.8% |
| All Others Subtotal | 25 | 33.8% |

Table 9 identifies the financial implications of the new arrangements supporting people that transitioned in 2016. It shows that in only 10.8% of the cases where people transitioned (8 people), were providers able to achieve this on a cost neutral basis. This is a significant reduction in the numbers identified as transitioning on a cost neutral basis compared to 2015 in which 21 people transitioned without additional resources. 2015.

Service providers noted that in over 44% of transitions completed in 2016 there was a cost implication. It can be noted that in a similarly large percentage of cases (44.6%), there was no information given to indicate the financial impact of transitioning. Further work will be needed in 2017 to gather this information for all transitions, alongside the work on outcomes for the individuals, as this is critical information used for budget planning and to measure the impact of the policy.

| Table 9: Financial Implications of new Arrangements completed in 2016 | | |
|--|----------------------|-------------------------------------|
| Financial Impact | No. of People | % of those that transitioned |
| Achieved on a cost neutral basis | 8 | 10.8% |
| Recorded a cost implication | 33 | 44.6% |
| Not stated | 33 | 44.6% |
| Total | 74 | 100.0% |

Table 10 identifies the range of financial sources that were used to support the people that transitioned in 2016, across the 33 cases where this was specified. It shows that where arrangements were not cost neutral, these costs were met through the HSE in 48.5% of cases and from the service providers own additional resources in 48.5% of cases.

| Table 10: Funding sources used where transitions were not cost neutral | | |
|---|----------------------|-------------------------------------|
| Financial Impact | No. of People | % of those that transitioned |
| HSE | 16 | 48.5% |
| Service provider | 16 | 48.5% |
| Not stated | 1 | 3.0% |
| Total | 33 | 100.0% |

Table 11 identifies the most significant challenges that providers identified when supporting the residents who completed the transition in 2016. It suggests that no major challenges arose in 46 cases. There were no significant stakeholders objections identified as the primary challenge for any transition completed in 2016.

The data shows that the most significant challenge was funding which impacted in 17.5% of the transitions. In 7 cases (9.5%) HIQA registration issues were identified as a challenge to transitions. The role of HIQA and the issues arising are dealt with in some detail elsewhere in this report.

| 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 | 7 | 9.5% |
| Funding Issues | 13 | 17.6% |
| Non Availability of Suitable Accommodation | 6 | 8.1% |
| Stakeholders not agreeing to project (parent/ family) | 2 | 2.7% |
| None specified | 46 | 62.1% |
| Total | 74 | 100.0% |

5.2 Individuals who passed away during 2016

There were 96 people residents who passed away during 2016 whilst living in a congregated setting. Table 12 shows the percentage of those that passed away by age profile, the degree of disability and the levels of support provided to individuals.

This data shows that the residents who passed away came from a wide age range and had varying levels of disability. The only noticeable trends are that over 68% of those that passed away had high support needs and that nearly 50% of those that passed away were aged between 50 and 69 years of age.

| Table 12: RIP by Age, Degree of Disability and Levels of Support | | | | | |
|---|---------------|-----------------------------|----------------|--------------------------|---------------|
| Age Range | % | Degree of Disability | % | Levels of Support | % |
| 18-29 | 3.1 | Moderate | 28.1 | Minimum | 0.0 |
| 30-39 | 7.3 | Severe | 33.3 | Moderate | 16.7 |
| 40-49 | 14.6 | Profound | 27.1 | High | 68.7 |
| 50-59 | 29.2 | Phy. & Sens. | 3.1 | Intensive | 7.3 |
| 60-69 | 19.8 | Unknown | 2.1 | Not given | 4.2% |
| 70-79 | 15.6 | | | | |
| Over 80 | 8.3 | | | | |
| Not given | 2.1 | | | | |
| | 100.0% | | 100.00% | | 100.0% |

5.3 Admissions during 2016

Overall in 2016 the drop in the number of people living in congregated settings since the beginning of the year was 136 individuals. It should be noted that there were still some admissions, with 34 individuals recorded as new or return admissions to the congregated settings during the year.

| Age Category | No. of People | % of those Admitted |
|-----------------------|----------------------|----------------------------|
| Under 18 years of age | 0 | 0.0% |
| Aged 18 to 29 years | 7 | 20.6% |
| Aged 30 to 39 years | 2 | 5.9% |
| Aged 40 to 49 years | 7 | 20.6% |
| Aged 50 to 59 years | 7 | 20.6% |
| Aged 60 to 69 years | 7 | 20.6% |
| Aged 70 to 79 years | 2 | 5.9% |
| Aged over 80 years | 1 | 2.9% |
| No age given | 1 | 2.9% |
| Total | 34 | 100.0% |

An analysis of the profile of the individuals admitted in 2016 was undertaken. Table 13 identifies the age range of the people that were admitted during in 2016. Over 60% of admissions were for people between the ages of 40 and 70 but a further 7 (20%) were under 30. The data indicates that the average age of the people admitted in 2016 was 51 years old.

Table 14 identifies the support needs of the people that were admitted during in 2016. It confirms that 15 (over 46%) of people admitted have a moderate or severe level of disability.

The data indicates that 22 (over 52%) people admitted had a requirement for a high or intensive level of support. There were 18 people who required a high level of support with 13 having being identified as having a severe or profound level of disability.

| Table 14: Level of Disability of the People Admitted in 2016 | | |
|---|----------------------|----------------------------|
| Primary Disability | No. of People | % of those admitted |
| Mild | 3 | 8.8% |
| Moderate | 8 | 23.5% |
| Severe | 7 | 20.6% |
| Profound | 7 | 20.6% |
| Physical & Sensory | 3 | 8.8% |
| Not specified | 6 | 17.6% |
| Total | 34 | 100.0% |

Table 15 identifies the reason for the admissions made during in 2016. A large percentage of people admitted were already known to and supported by service providers, either living within the community based residential services or in on long term respite with a provider.

| Table 15: Reason for Admission of individuals in 2016 | | |
|--|----------------------|----------------------------|
| Reason Identified | No. of People | % of those admitted |
| From community service due to changing need | 3 | 10.0% |
| Conversion of respite placement (bed blocking) | 1 | 3.3% |
| Personal Health / Medical Reasons | 4 | 13.3% |
| From home due to change in carer circumstances | 2 | 6.7% |
| Unsuitable housing | 6 | 20.0% |
| Not specified | 14 | 46.7% |
| Total | 34 | 100.0% |

Table 16 identifies the type of settings to which people were admitted during in 2016. It shows that 76% of the people admitted went to placements on a campus, with 50% admitted to Large Campus.

| Table 16: Type of Placement to which individuals were admitted in 2016 | | |
|---|----------------------|----------------------------|
| Type of Placement | No. of People | % of those admitted |
| Large campus | 17 | 50.0% |
| Part of a cluster on Campus Site | 9 | 26.5% |
| Community House | 6 | 17.6% |
| Other | 2 | 5.9% |
| Total | 34 | 100.0% |

A review of the people who were admitted / readmitted to congregated settings during 2015 was undertaken and an update on the current status of these individuals is provided in Appendix 3.

6. Status of Congregated Settings at End of 2016

At the 31st December 2016 there were 2,579 people who remain living in the congregated returned on the master data set. With the changes in the population, since the *Time To Move On From Congregated Settings* 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 2016 and the type of services that remain.

6.1 Profile of Residents remaining in congregated settings at end of December 2016

Table 17 summarises the age profile of the residents that remained in congregated settings at the end of 2016. 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 *Time To Move On* report said that about half the residents were in the age range 40-60 years, with a further 20% aged over 60. Whilst the 2016 data confirms that the age range 40-60 years is similar the numbers aged over 60 has increased to 30.6% of the total residents.

| Age Category | No. of People | % of People |
|----------------------|----------------------|--------------------|
| under 18 | 13 | 0.5% |
| 18-29 years of age | 101 | 3.9% |
| 30-39 years of age | 334 | 13.0% |
| 40-49 years of age | 618 | 24.0% |
| 50-59 years of age | 707 | 27.4% |
| 60-69 years of age | 521 | 20.2% |
| 70-79 years of age | 217 | 8.4% |
| Over 80 years of age | 50 | 1.9% |
| No age given | 18 | 0.7% |
| Total | 2579 | 100.0% |

Further analysis confirms that almost 59% of the resident population is now over 50 years old. Whilst some older residents have passed away, we are seeing that people with disabilities are living longer with 10% aged over 70 years of age, made up of 217 people in their 70's and a further 50 people now aged 80 or older.

Chart 2 captures the age profile of the population in 2016 and 2009, across the “decade age ranges”, demonstrating the shift in the age profile of the residents. The most populated age bracket has shifted upwards from 40-49 years to 50-59 years. In 2009, 1,113 were in the 40-49 age bracket representing 27.6% of the population, now in 2016, the largest group fall into the 50-59 age bracket with 707 residents, which is 27.4% of the congregated setting population.

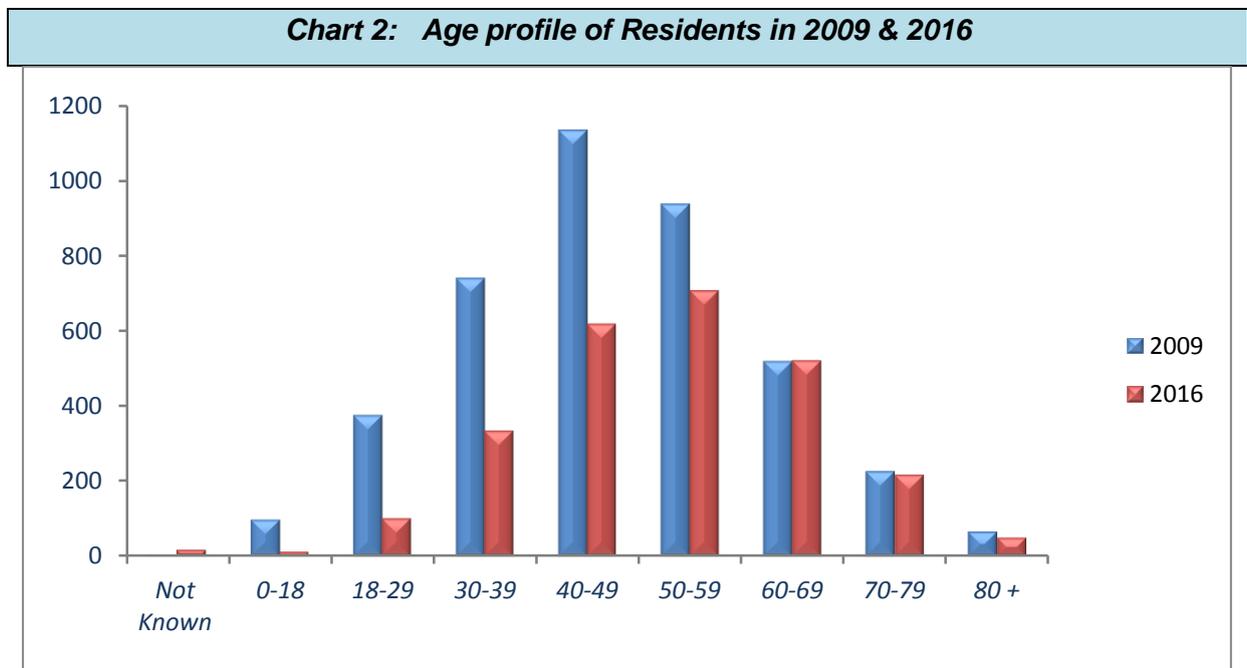


Table 18 summarises the level of disability of the residents that remained in congregated settings at the end of 2016. The data reflects that the population currently living in congregated settings continue to have high levels of disability, with over 56% identified as having a severe or profound level of disability.

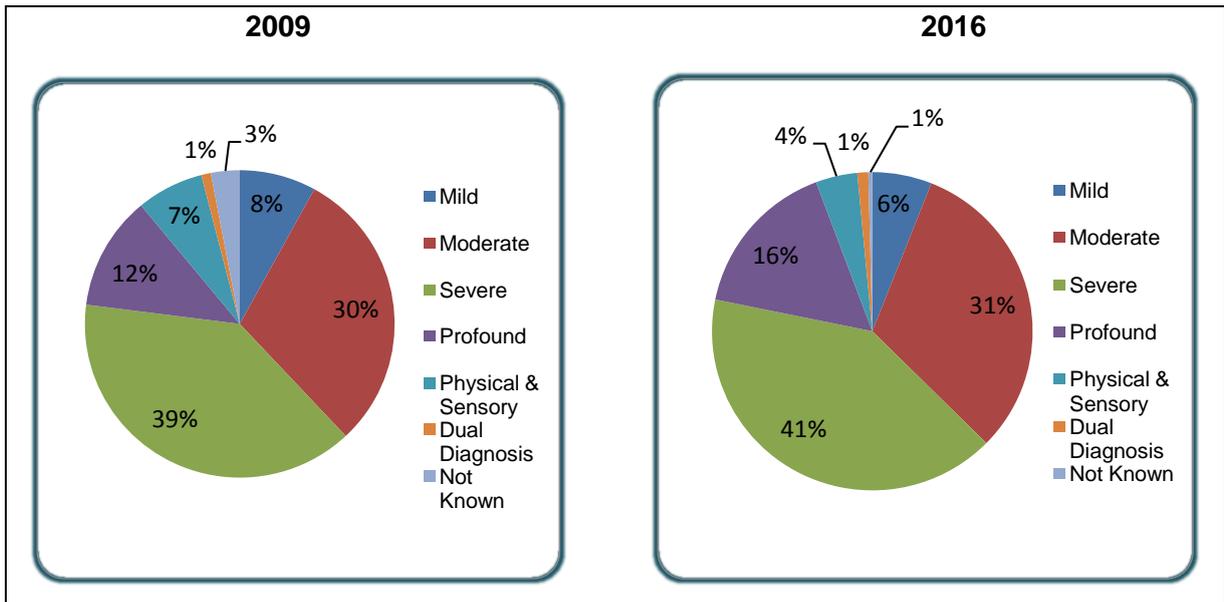
| Table 18: Level of Disability of the People in Congregated settings at end of 2016 | | |
|---|----------------------|-----------------------|
| Primary Disability Identified | No. of People | % of Residents |
| ID/ MH | 29 | 1.1% |
| Borderline | 2 | 0.1% |
| Mild | 155 | 6.0% |
| Moderate | 810 | 31.4% |
| Severe | 1051 | 40.8% |
| Profound | 415 | 16.1% |
| Physical & Sensory | 109 | 4.2% |
| Not specified | 8 | 0.3% |
| Total | 2579 | 100.0% |

A comparison between 2009 and 2016 is shown in Chart 3, looking at the level of disability recorded for the residents. There has been a slight increase in the percentage of people in congregated settings that present with a severe disability, up from 39% to 41% of the overall population.

The greatest increase is the 4% rise in the percentage of residents that have a profound level of disability from 12% in 2009 to 16% in 2016. Overall, even though the percentage of residents with a severe or profound disability has risen to 57% of the total the actual number of people with this level of disability has fallen to 1,466 compared to 2,164 in 2009.

The largest decrease was seen in the number of people whose primary disability is a physical and sensory disability. In 2009, there were 297 people identified as having primary physical and sensory disability, which accounted for 7% of the congregated setting population. In 2016 this has fallen to 109 people or 4% of the congregated settings population, which indicates that there has been substantially more activity in supporting this group to transition alongside other changes in this population.

Chart 3: Level of Disability of Residents



In relation to people identified who have a mild disability, although in both cases this cohort accounts for 7-8% of all the residents in congregated settings at that time, the overall numbers have fallen from 337 in 2009 to 157 in 2016, suggesting again that there has been significant movement for residents with this level of disability.

In addition to the primary disability, Table 19 outlines the level of support required by people remaining in congregated settings at the end of 2016. Almost 70% require a high level of support with almost 6% requiring intensive support.

| Primary Disability Identified | No. of People | % of Residents |
|-------------------------------|---------------|----------------|
| Low | 154 | 6.0% |
| Minimum | 29 | 1.1% |
| Moderate | 450 | 17.4% |
| High | 1791 | 69.4% |
| Intensive | 151 | 5.9% |
| Not specified | 4 | 0.20% |
| Total | 2579 | 100.0% |

A further analysis and cross reference of information on those requiring a high level shows that 766 of these individuals are aged 40 or under (42%), 508 (28%) are aged between 50-59 with 506 individuals (28%) 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, is still improving and as a result there will be long term resource implications in supporting these people with high support needs who are still relatively young.

Table 20 examines the prevalence rate of people with high medical needs/medical frailty or behaviour that challenge. It can also be noted that 2,081 individuals identified have a high or intensive support needs and of these 1,392 have a severe or profound intellectual disability

| Table 20: Prevalence Rates of High Medical Needs and Behaviours that Challenge | | |
|---|----------------------|-----------------------|
| Length of Stay as at 31/12/2016 | No. of People | % of Residents |
| 2009 | 4099 | 100% |
| High Medical Needs /Medical Frailty | 723 | 17.6% |
| Behaviours that challenge | 1089 | 26.6% |
| 2016 | 2579 | 100% |
| High Medical Needs /Medical Frailty* | 310 | 12.0% |
| Behaviours that challenge* | 736 | 28.5% |

**The 2009 figures were based on a survey completed by service providers. The 2016 figures are based on the master data set question where details of additional disabilities could be identified. As any relevant information could be provided there was a wide range of information returned that included a range of diagnoses, medical conditions, epilepsy, high nursing, complex care needs, autism, physical and mental health conditions. For the purposes of comparison between 2009 and 2016, the prevalence of the terms high medical needs, frailty and behaviours that challenge were isolated. Please note, the use of these terms is not mutually exclusive, so it is possible for a person to be counted under both headings.*

Finally, an analysis was done to look at how long the individuals who still live in congregated settings, having been living in these arrangements. This information is provided in Table 21 which shows that over 70% of individuals have now been living in a congregated environment for over 20 years (not including those for whom no information is available).

Importantly and on a positive note, there are also just fewer than 80 people who have been living in a congregated setting less than 4 years, which demonstrates that the practise of admitting to a congregated setting since the policy commenced in 2012 has slowed. As the rate of admission has been around 1-2%, these figures also demonstrate that for those that have been admitted, these are often short term arrangements where providers support the individuals with end- of-life care or through a particular crisis or change in needs before they are supported to move back to the community.

This is particularly laudable, as it demonstrates the commitment of providers to the policy and their recognition of 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 21: Length of Stay in Congregated Setting | | |
|--|----------------------|-----------------------|
| Length of Stay as at 31/12/2016 | No. of People | % of Residents |
| Admitted during 2016 | 29 | 1.1% |
| 1 to 4 yrs | 49 | 1.9% |
| 5 to 10 yrs | 135 | 5.2% |
| 11 to 20 yrs | 389 | 15.1% |
| 21 to 30 yrs | 372 | 14.4% |
| 31 to 40 yrs | 368 | 14.3% |
| 41 to 50 yrs | 388 | 15.0% |
| 51+ yrs | 285 | 11.0% |
| Not stated | 564 | 21.9% |
| Total | 2579 | 100.0% |

6.2 Changes to Congregated Setting Location Profile by end of 2016

At the end of 2016 there were 21 service providers, returning information on 60 services that collectively are made up of 391 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 communal bathroom facilities. There are also a small number of dormitory-style units still open that provide very little privacy or personal space for individuals.

A full breakdown of the 60 services and the separate units, by service provider and CHO Area is provided in Appendix 4.

During the year one congregated setting closed completely. This was the Grove House Centre in Cork city, run by the HSE, which had over 30 residents when the report was written in 2011. Details of how the closure was achieved are given in Appendix 5.

Whilst no other locations have closed entirely, the overall reduction of 136 individuals living in the congregated settings has meant that service providers have been able to reduce the number of residents in particular units and support internal transfers. This has seen individuals supported to live in smaller groups and/or alongside others with whom they are more compatible. This can improve the safety of services for individuals, improve opportunities for friendships and activities and enables providers to deliver more person-centred care aligned to individual interests and support needs.

6.3 Changes in the locations identified from 2009-2016

An issue that has continued to arise in the tracking of the congregated settings population is the on-going fluctuation in the number of units identified as falling under the policy. This arises for the following reasons:

- Unintentional omission of specific units / settings since the original report.
- Differing opinions on the status of some centres in terms of whether the *Time To Move On From Congregated Settings* policy should be applicable, i.e. specific

stand-alone nursing home type facilities for people with disabilities.

- Cross over with Mental Health Services. Some centres originally identified were designated mental health services that also supported people with disabilities; others were de-designated services supporting people with disabilities but still funded and/or managed by MHS.
- Identification of clusters within the community that were effectively small campus's and/or operated as a single unit.
- Changes in the number of residents in specific settings that led to services either falling below or exceeded the threshold of 10 residents.
- Identification of condition-specific residential services, such as residential services for people with Autism, Nursing Home type units specifically for people with disabilities and those for Deaf & Deaf/Blind people.

6.4 Reviewing Settings Identified and Tracked under the Policy

Work was undertaken with the providers at an administrative level in 2015 and again in 2016 to improve the understanding of the criteria that determines whether a setting is classified as congregated. This has reduced the frequency of changes identified in 2016. Currently there are a number of services for which providers are seeking exemptions due to the nature of the service provided and we are aware of a small number of anomalies in terms of what is being captured in the data. A review will commence in 2017 that will:

- Examine the appropriate delivery of residential services for people with disabilities that have significant co-morbidities.
- Address residual anomalies in the data i.e. where two similar services exist and one is included in the Master Data set and another is not due to policy interpretation.
- Examine how other congregated locations that are not included in the Master Data Set are managed under the policy. These locations would include services where people with disabilities are living in settings such as intentional communities; farm based services, certain condition specific/ specialised services, mixed MH/Disability services.

6.5 Current Living Arrangements

The information provided, looks at the living arrangements for the individuals remaining in the congregated settings, in terms of the numbers of individuals living together:

An analysis of the current living arrangements for the individuals that remain within a congregated setting at the end of 2016 is given in Table 22. This specifically shows the number of people living within the different types of arrangements. This demonstrates that 73% of people, 1,888 individuals are now living in a unit with less than 9 others, within a large cluster or on a campus, compared to 63% in 2015 (1,648).

This shows that reconfiguration within settings has led to 240 people now living in smaller groups of less than 10 and that the number living in single person arrangements, or groups of no more than 4 has remained constant at 255 people.

There are still almost 700 individuals that are living in larger groups where there are 10 or more people with a disability together but this is a marked improvement on the figure of 1,069 people in 2015.

Table 22: Living Arrangement of People in congregated settings at end of 2016

| Type of Living Arrangement | No. of People | % of Residents |
|--|---------------|----------------|
| With 15 or more others (part of a campus or standalone unit) | 328 | 12.7% |
| With 9 - 14 others (part of a campus or stand-alone unit) | 363 | 14.0% |
| With 4 - 8 others (unit on a campus) | 1633 | 63.3% |
| With 1 - 3 others (unit on a campus) | 170 | 6.5% |
| Alone (unit on a campus) | 85 | 3.3% |
| Total | 2579 | 100.0% |

In order to put the information on the number of individuals sharing a home together into more context, data is provided in Table 23 on the overall size of the campuses where people live.

By the end of 2016 there was drop in the number of people living on campuses with over 100 residents, from 961 in 2015 to 725 in 2016 resulting in the number of people living in

campuses with 50-99 increasing from 713 to 817 as campuses changed size classification. These changes reflect the incremental improvement in settings as beds are being suppressed once vacated either through natural changes or active transitions.

| Table 23: Size of Settings remaining at the end of 2016 | | | |
|--|---|---|--|
| Size of Campus/ Cluster by overall resident numbers | No. of Services in this category | No. of People living in this sized setting | % of Residents living in this sized setting |
| Campus with over 100 residents | 6 | 725 | 28.1% |
| Campus with 50-99 residents | 11 | 817 | 31.7% |
| Campus/ Cluster with 30-49 residents | 7 | 252 | 9.8% |
| Campus/Cluster with 10-29 residents | 47 | 724 | 28.1% |
| Setting with under 10 residents | 9 | 61 | 2.4% |
| Total | | 2579 | 100.0% |

As can be noted from Table 24, in some cases the number of residents within a setting/campus has now fallen with less than 10 people remaining, but as they continue to be accommodated with a centre/campus environment that previously housed many more people, these locations are not considered as appropriate accommodation in terms of being a person's own home that is within the community.

| Table 24: Congregated Settings with less than 10 residents by 31/12/2016 | |
|---|----------------------------|
| Name of Setting | Number of Residents |
| HSE Donegal – Sean O’ Hare, Stranorlar | 6 |
| Cheshire Ireland, O’Dwyer Home, Mayo | 6 |
| St John of Gods, Carmona, Bray | 9 |
| HSE Donegal – Cill Aoibheann | 9 |
| Cheshire Ireland, Sligo, | 7 |
| Sunbeam Dunavon, Rathdrum , | 8 |
| Sunbeam, Hall Lodge | 2 |
| Muiroisa Foundation, St Marys Centre, Devlin | 5 |
| Cheshire Ireland, Tullow, Co. Carlow | 9 |

7. Analysis of 2016 Activity: Challenges & Solutions

During 2016 there was a particular focus on achieving moves from priority sites where there are significant issues in achieving compliance with the National Standards for Residential Services, as regulated by HIQA. In total 74 people completed their transition during the year and whilst this was below the national target, it should be noted that service providers identified that at least 87 other individuals were still actively being supported to develop their transition plans at the end of 2016 with housing solutions for 197 residents being progressed under the HSE Disability Capital Funding Programme and 20 residents under the Capital Assistance Scheme Fund.

Information provided by service providers and CHO teams highlighted that a number of significant challenges impacted on the progress made in the calendar year. These challenges fall into three categories namely, accommodation, communication and revenue funding issues. The particular issues arising under of each of these headings is discussed in detail below.

7.1 Accommodation Challenges

As new capital funding became available in 2016 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 DOH, DECLG and 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 emerged. These included:

7.1.1 Sourcing Accommodation

In 2016 the CAS and HSE Capital funding streams were targeted towards the acquisition of existing properties rather than new builds in order to achieve a faster completion of projects. The reality on the ground for the service providers was that very few suitable properties were available and that those on the market often attracted the interest of other bidders. In several cases potential properties were lost when the services were outbid or the service providers were unable to secure project approval in time to make an offer. There were also a few instances where vendors withdrew at a late stage, preferring not to sell to a service provider who would be supporting people with disabilities.

One provider has advised that they viewed in the region of 50 properties in their attempt to source homes, which is a time consuming and expensive process for the local teams. Overall a review of the HSE Capital Funded Projects being progressed during 2016 indicates that there were 59 properties being tracked at the end of 2016:

- 30 properties had been purchased by end of 2016
- 15 properties were on track for purchase at end of 2016
- 3 properties fell through (outbidding)
- 8 properties - withdrawn over unsustainable escalating costs / unsuitable accommodation
- 1 property- withdrawn from sale by vendor

7.1.2 Lead- in time for HSE Capital Funded projects

The availability of new capital monies in the first Quarter of 2016 was a welcome boost to the HSE and Service Providers seeking to support people to transition from congregated settings. However most projects allocated funding in 2016 were not completed in time to support individuals to move within the calendar year due to the time needed to complete these projects ready for occupation.

A review of the progress of the HSE disability capital funded projects demonstrates that in the region of 12 months is required from the time a property is found until it will be ready for use. This time period does not take into account the time that may be spent searching for a suitable property, making bids and negotiating prices prior to a sale being approved. The long lead-in time of 12 months arises due to:

- Time taken before HSE takes ownership of property- achieving sale agreed, exchange of contracts and acquiring vacant possession of property
- Determination and agreement on schedule of works for refurbishment of property
- Tendering process for any refurbishment works
- Completion of refurbishment works. This may vary from extensive adaptation or moderate level of re-fit, decoration and furnishing
- Undertaking furnishing/ fit out. A process has to be undertaken to agree required inventory of goods and source these for each property in line with the National Financial Regulations and agreed procurement processes. For many large furniture items there can be a waiting period before delivery. Where suitable goods are not

available on contract, additional time is needed to source these items in line with procurement processes

- Working with the residents to ensure they have an input into their new home in terms of selection of colours, soft furnishing, pictures etc.
- Where necessary engaging with HIQA around the registration of a new property as a designated centre
- Leasing Agreement with Providers.

The HSE Estates & Oversight group is monitoring the progress of projects to ensure that where possible streamlining of the processes can be facilitated.

7.1.3 Accessing Capital Assistance Scheme (CAS) Funding

The “CAS call” for applications for CAS funding went out to housing authorities in June 2016, (Housing Circular 29/2016). The revised process required applications to meet the revised *Specific Requirements* for eligibility included as laid down in Housing Circular 45/2015 and to provide certification supporting the application from the HSE, service provider and approved housing body. The process also required both the local Housing Authority and the DHPCLG to review and approve the application, which can be a lengthy process taking several months to complete.

Due to the timeframes involved in securing approval and drawing down funding the approved housing bodies and service providers noted that within a fast-moving housing market there is very little potential to secure houses through acquisition using CAS. This is less of an issue for proposals that involve site acquisition and construction.

As detailed earlier the introduction of the specific requirements as laid down in Circular 45/2015 included a requirement for supporting documentation from the HSE changed the CAS submission process in 2016. There were some difficulties identified in interpretation of the Circular by Local Authorities particularly for those not familiar with congregated settings or the support and housing needs of the residents.

As a result there was a low uptake under the CAS funding stream to support people transitioning from a congregated setting in 2016 both in terms of the number of applications made and the final number of projects approved. In total, 7 projects were funding for a total of 20 residents at a cost of €2.2million.

7.1.4 Property Adaptation

A number of challenges arose during 2016 in relation to determining the appropriate level of adaptation and refurbishment needed in specific properties and the cost and time implications of this. These challenges centred on the following issues:

- The differing professional opinions in relation to how individual resident needs should be met and the impact of this on adaptation briefs and costs
- The level of “future-proofing” being included in property development
- The interpretation of HIQA regulations and Inspector comments and the impact of this on house design and fit out requested / required
- The interpretation of the Code of Practise on Fire Safety in Community Dwellings and fire and building regulations
- The interpretation of planning permission requirements
- Securing Contractors to undertake work and achieving the best price, time and quality of work in line with tender.

The HSE Disability & Estates Oversight group are developing guidance supporting local services and HSE teams to manage these issues.

Under the *Time To Move On From Congregated Settings* Subgroup a *Making Homes* work stream will commence in 2017, to develop a guidance document that will signpost best and appropriate practise 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.

7.1.5 Impact of Regulation by HIQA

During 2016 HIQA continued the process of inspecting all residences against the Regulations to register services and address issues of non-compliance. The feedback from providers continues to be that overall regulation of the disability residential sector is welcomed as it is supporting and driving a structured improvement in the services. The inspection process has had a knock on effect on the implementation of the *Time To Move On* policy.

7.1.6 Continued Capital Investment in Congregated Settings

As inspection reports in some centres continue to indicate that significant infrastructural work is required there can be a dilemma in determining the level of renovations that should be undertaken in settings are destined to close. This is particularly challenging in settings where the closure is still some time away and work is needed to secure registration. In 2016 there were significant renovations in some congregated services that were costly and in some cases disruptive to residents. It can be noted that whilst this investment might ensure a congregated setting achieves registration and meets a basic standard environmentally, it does not create a home for the resident and it is highly unlikely they will have had any input into the changes/improvements.

From a communication perspective, this investment sends a mixed message to stakeholders, which can undermine working relationships and engagement around the policy. There is a risk that some stakeholders will choose to see any investment in the congregated settings as an opportunity to fight for a continuation of the current service and further improvement of the existing buildings.

It has also been noted that in some cases the investment in existing services results in stakeholders dismissing the plans for decongregation as notional and “something that will never happen”, as it appears illogical to invest funding in services that are due to close. Managing this as part of a co-ordinated communication plan is critical to ensure that all stakeholders are effectively engaged and appropriately informed, which will help to ensure they can play a positive role in supporting policy implementation.

7.1.7 New Registration

HIQA is supportive of current public policy which is aimed at facilitating residents to move from congregated settings to more appropriate living arrangements. As part of this policy, residents may move from a designated centre to another residential arrangement. It is the responsibility of the provider to identify whether the new residential arrangement constitutes a designated centre or not.

All new residential settings that are deemed to meet the criteria for registration as a “designated centre” must be fully registered before they can be occupied. HIQA endeavour to facilitate the registration of new centres within 6-8 weeks and in some exceptional cases registration is fast-tracked. On occasion, HIQA may identify issues for attention prior to registration, which range from clarifications on staff rostering to information on house

policies, fire plans, technical specs etc. and these may delay the opening of houses and the transitioning of individuals to their new homes at the planned time.

Evidence from 2016 identifies that there were very few delays encountered once the registration process had commenced with HIQA on new properties. However, delays did arise as a result of providers taking additional time to complete projects prior to engaging with HIQA. In several cases, the housing specification and service changes implemented by providers were not required to achieve registration as a designated centre. Whilst some of these measures represent reasonable “future-proofing” others led to greater cost and time being incurred on a project that could have been avoided.

A “Making Homes” work stream is examining these issues in 2017. A working group will be looking in detail at all the issues that providers need to address once the funding mechanism for the housing is determined, through to when a person moves in. This will cover issues such as fit-out, furnishings, adaptations, registration, building regulations, financial arrangements etc. The group will consult and liaise with key stakeholders including HIQA, HSE Estates, DECLG, DOH and others to ensure that all aspects are considered. The “Making Homes” working group will develop a signposting document that will be added to the Implementation Framework as a resource for providers and staff.

7.2 Communication Challenges

The importance of supporting meaningful communication and engagement as part of the *Time to Move On* change programme cannot be understated. In 2016 this became a significant challenge in some locations and it is anticipated that in 2017 and beyond this will continue to be one of the most critical areas in supporting the delivery of the policy.

7.2.1 Supporting the Residents and their Families

Where difficulties have arisen in 2016, in many cases there has been a lack of appropriate and meaningful engagement or dialogue with individual families. Service Providers need to prioritise engagement and remain vigilant, to ensure they are addressing the specific concerns of each family which often centre on issues such as safety in the community, long-term security of service and retaining access to current services. Service Providers also need to support families and individuals to visualise the positive gains for the person once they live in the community, focussing on how their day to day life will change with new opportunities emerging, rather than only discussing what might be perceived as being “lost” by leaving the congregated setting.

There is substantial evidence from the Service Providers that have moved to the community model that the communication and engagement process must be actively managed at a local level and on an on-going basis with individual families. Similarly, attention must be paid to 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 will involve the co-ordinated effort of the service provider team who will actively manage the communication and engagement process and cannot be achieved by one staff member working in isolation.

Recognising the importance of communication and the investment of time and energy required by a service to deliver this, one provider recently logged all the contacts (telephone calls, emails, meetings etc.) associated with supporting an individual to move to the community. In total 165 contacts were made in relation to the move for one person and these ranged from short calls to Estates Agents through to meetings with the family and planning meetings with the person themselves.

It is interesting to note that this service provider has extensive experience of decongregating and operates a large community-based model of service alongside the congregated setting. The service identified this as a reasonably "straight-forward" transition with no resistance encountered. Overall this example suggests that focussing and managing the communication and engagement around each transition can often be critical to achieving a successful move.

7.2.2 Supporting staff who work in congregated setting

As part of the Project Actions Plan documentation suite, all the priority sites had been directed to focus on Workforce planning/ HR and staff engagement as a key work stream in 2016. During the year there was no evidence to indicate that staffing issues had directly delayed any transitions. However it was notable that by the year end there was also no evidence of meaningful engagement with staff in several large congregated settings where reconfiguration of the workforce will be required.

In some cases transitions in 2016 were achieved as individuals were primarily supported by agency, contract or temporary staff. The suppression of vacant posts in the congregated settings enabled the service providers to support individuals to move into the community

without needing to formally change the status quo of the existing staffing structure. This allowed service providers to support residents to move without the risk of delays due to HR issues. It also proved to be an effective mechanism to create a positive culture of person-centred community living and to mitigate against the transfer of any outdated or inappropriate practise from the congregated setting. However this is not a sustainable long term solution and during 2017, service providers will need to engage with the core staff teams in the congregated settings to determine how the workforce will be reconfigured to support the residents as they move into the community.

One organisation that has made significant progress in decongregating has for many years adopted an approach whereby every vacant post that arises is critically scrutinised and the opportunity taken to utilise the natural turnover in staff to bring about a change in skill mix, and working patterns. Over time this is an effective approach to reconfigure the workforce, but also an approach that encourages managers and team leaders to look critically at how residents are supported and how staff resources can be most effectively deployed to meet their needs.

7.3 Revenue Funding challenges

A key feature of the transitions achieved and commenced in 2016 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.

7.3.1 Service Reform Fund -Supporting Change through Leaders & Frontline staff

The 2015 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 practise through practical work between the training sessions. Collectively these additional transitional staff resources and training investments are building the capacity within the congregated settings workforce and support structures to bring about meaningful change as people transition out.

Unfortunately in 2016 delays arose in releasing some of the SRF funding which prevented progress being made in relation to the filling of any posts identified in the proposals. As many of these posts were critical front line positions, with staff identified to work on a one-to-one basis and support residents through the transition, the lack of funding did directly impact progress in 2016.

7.3.2 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 2016 this statement is no longer valid in all services for a number of reasons:

Changing Need

The profile of the residents in congregated settings has changed; they are now an older group with more complex support needs

Deficits in Existing Settings

As evidenced through the HIQA inspection process the quality and standard of care provided in many of the current congregated settings is not adequate. Many of the service providers do not have sufficient resources to address environmental issues, to deliver safe care or to provide individuals to access supports /activities on an individual or group basis. Additional investment would be required in these services to address these deficits in situ, without any move to community living.

Lack of a Meaningful Day

In line with the *New Directions* policy, the *Time To Move On* policy states that the people transitioning from the congregated settings will be supported to access a meaningful day. It t
Many residents in congregated settings do not currently have access to or attend a full time day service. It is recognised that delivering the *New Directions* policy will not be cost neutral and on this basis it is accepted that there will be a cost implication for each person who transitions from a congregated setting to community living and requires support to access a meaningful day.

NDAT Evidence

During 2016 work was undertaken by the National Disability Operations Team to administer the National Disability Analysis Tool. This tool is a desktop process that produces a score for each resident based on a series of enquiries in relation to each person's support needs. The known revenue cost for the unit each person lives in, is identified and a number of other factors are noted as indicators of quality outcomes.

From the information collected to date on over 1000 individuals, there is clear evidence to show that the support needs of those in congregated settings is significantly higher than that of the individuals currently living in the community. This does not suggest in any way that community living is less appropriate for those with higher support needs, but merely demonstrates that historically services have been delivered on a congregated setting basis for many of those who present with higher support needs. The tables below demonstrate the difference in the support needs and profile of the residents in congregated setting compared to the population supported within the community residential services.

Of the NDAT sample population, Table 24 below looks at the age profile of residents currently resident in the congregated setting compared to the people who are in community based residential services. Overall 60.1% of the people in congregated settings are over 50 years of age, whilst only 36.4% of those living in community settings are over 50 years of age. This would indicate that support needs associated with ageing and the emergence of changing needs is currently more prevalent amongst those in the congregated settings.

Table 24: Age Profile of Residents in Congregated & Community Settings (NDAT)

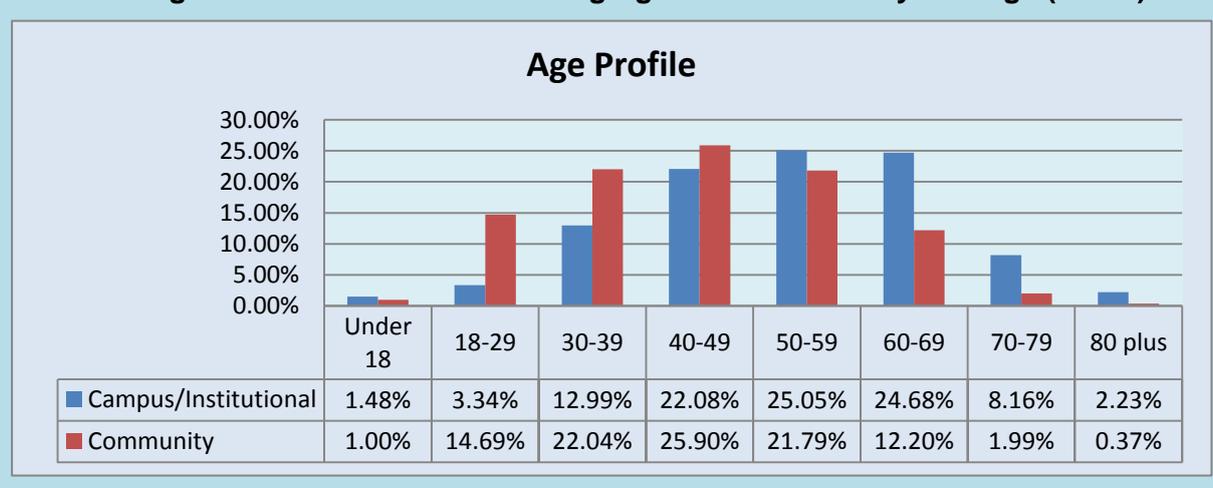


Table 25 looks at the level of intellectual disability of residents currently resident in the congregated setting compared to the people who are in community based residential services. The ratio of people with a severe or profound level of disability is over 2:1 for congregated versus community settings. Again this would indicate that support needs for those in the congregated settings are significantly higher than the current population living within the community.

Table 25: ID Level of Residents in Congregated & Community Settings (NDAT)

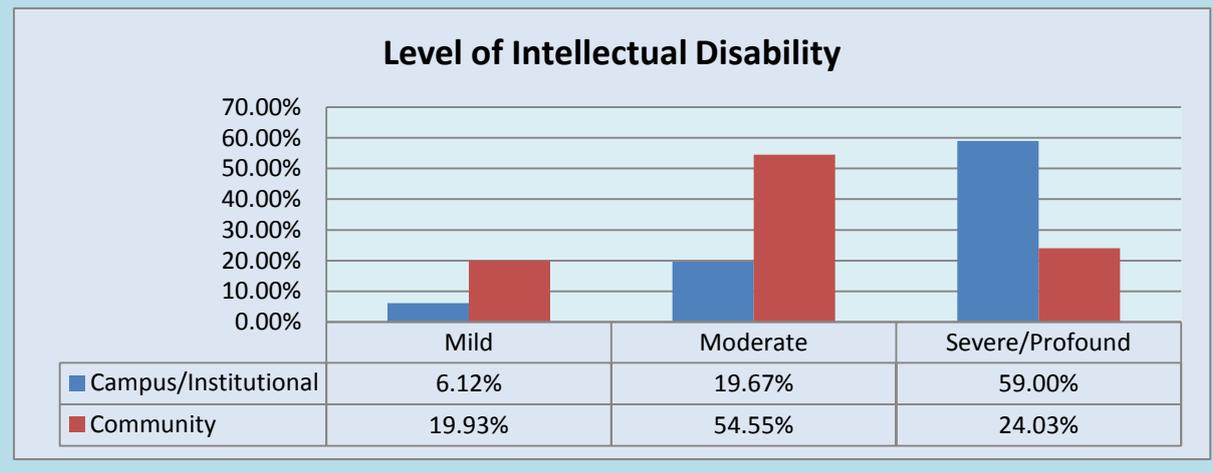
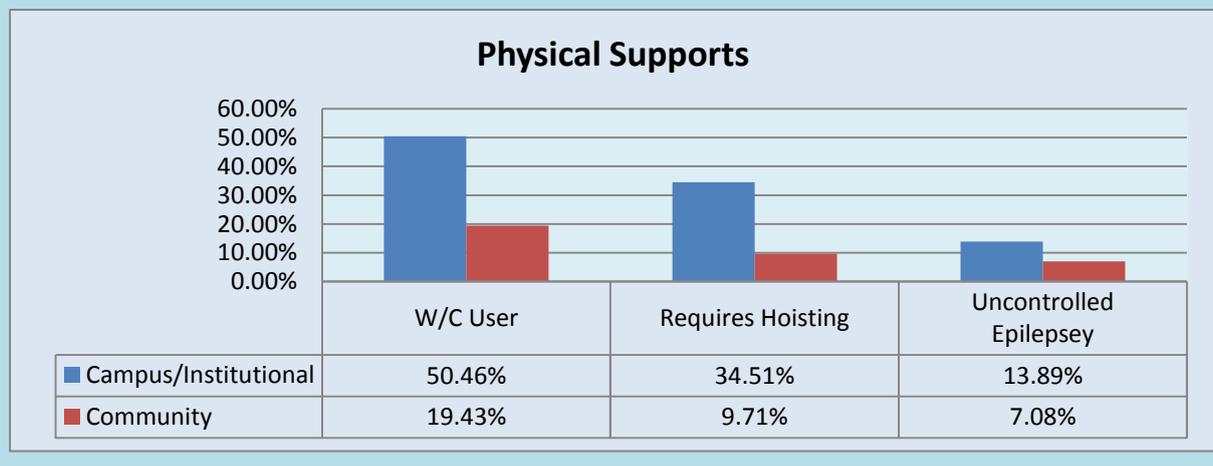


Table 26 looks at the physical support needs of resident in the congregated setting compared to the people who are in community based residential services. The requirement for full hoisting, support with uncontrolled epilepsy and support as a wheelchair user in congregated settings is at least double that of people in the community settings. This indicates the support needs for those in the congregated settings will be higher than that seen with the current population living within the community and also indicates that the level of adaptation and equipping will be higher to meet these needs.

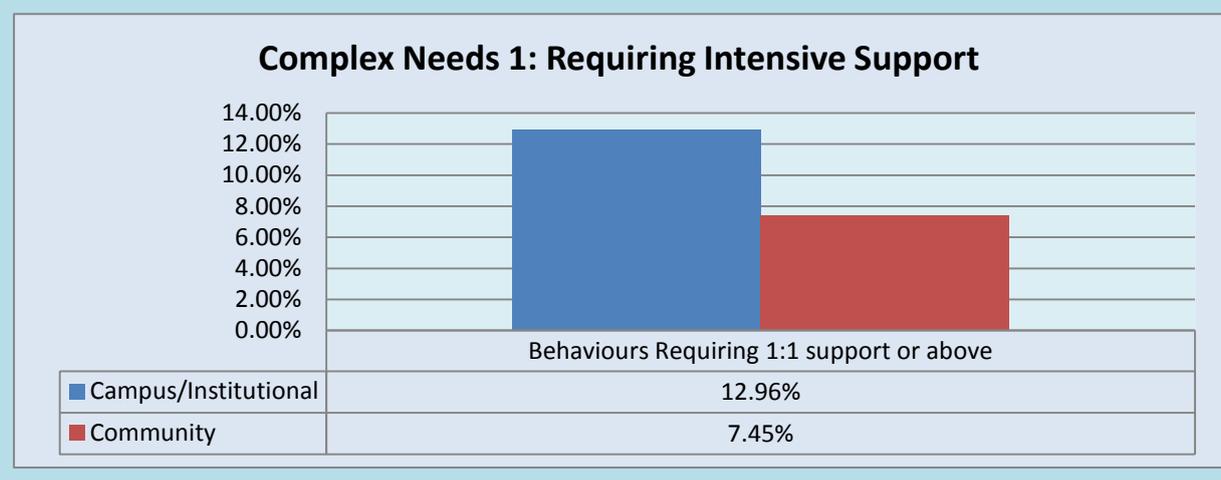
Table 26: Physical Support Needs in Congregated & Community Settings (NDAT)



Finally, Tables 27 and 28 look at the level of complex needs identified for residents currently living in the congregated settings compared to the people who are in community based residential services. The two specific areas examined were the incidence of residents who are prescribed psychotropic medication (with or without a diagnosed mental health condition) and the number of residents who are supported for behaviours that challenge, with a 1:1 staff ratio or more.

The levels of behaviours that challenge are notably higher within a congregated setting. It can be argued that the congregated setting environment will be a factor that influences the level of behaviours that challenge amongst the residents in these locations. Case studies are showing that the number of incidents of behaviours that challenge has markedly decreased and ceased entirely for some people once they move and settle into homes in the community. The pre and post transition assessments being undertaken as part of the *Moving In* study under the Transforming Lives Programme is examining the outcome of the transition to community for those leaving the congregated settings. This study will provide an evidence base to demonstrate the impact that moving to the community has on those with behaviours that challenge and the associated support needs.

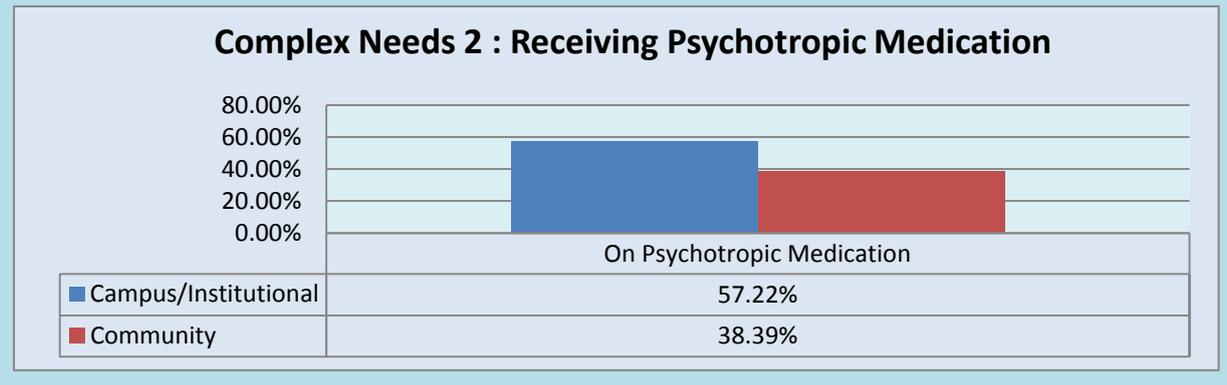
Table 27: Complex Needs of Residents Requiring Intensive Support (NDAT)



However, it is also important to note that as the population in congregated settings have higher levels of disability, physical and mental health support needs and changing needs associated with ageing, there are many other factors influencing the behaviours that challenge for those in congregated settings than just the environment.

Table 28 identifies that a greater percentage of residents in congregated settings than in community settings require psychotropic medication, which suggests they have greater need for mental health services and medical supervision. The long term implication arising from this is that as these individuals move to the community they will need continued access to mental health supports and MHID teams that have the capacity to meet the needs of people moving from congregated settings.

Table 28: Complex Needs of Residents Receiving Psychotropic Medications (NDAT)



Early evidence is indicating that the level of funding currently supporting residents in congregated settings is far less than the funding that is attached to residents living in the community where there is a similar support needs score based on the NDAT tool. Although further work and data collection is needed to expand on this early finding, it does suggest that there will be a cost implication going forward, to enable services to provide a safe, high quality service for people who transition to the community.

8. Priority Actions and Work Plan for 2017

8.1 National Service Plan 2017 and National Social Care Operational Plan 2017

The HSE 2017 *National Service Plan* (NSP) and *the National Social Care Operational Plan* (NSCOP) 2017 identify that there will be a continuation of the accelerated implementation of the *Time To Move On* policy. There is a target of at least 223 individuals supported to move to community settings from 21 sites and this includes all the individuals that were identified for transition who did not complete their move in 2016, along with an additional 160 people. In most cases the transitions continue to be targeted from the priority sites, where there are significant concerns around compliance with the National Standards for Disability Residential Services.

NSP 2017 also identifies that the disability sector will:

- Enable service improvements that will focus on compliance with regulatory standards in agreed priority sites in conjunction with HIQA
- Progress implementation of the recommendations of the *McCoy Review – Áras Attracta*
- Implement plans to meet housing requirements for those transitioning to the community with approved housing bodies, housing authorities and HSE Estates

The NSCOP 2017 identifies a number of specific actions to be undertaken to support the 223 transitions targeted for completion in NSP 2017:

- Complete the implementation plans that will identify how service providers will transition residents into the community in line with policy, with the key actions and milestones to be achieved in 2017 – 2018.
- In line with National Guidelines etc. that CHOs will ensure the plans:
 - Deliver transition plans and outcomes reflect individual's will and preference for a *good life*
 - Support individuals to integrate in their community,
 - Consult with staff and progress development within existing agreements and frameworks to ensure best and earliest outcomes for individuals
 - In collaboration with residents, identify and progress housing so that targets are met on time

- Ensure all Service Providers have developed specific local communication plans
- Engage in the Service Reform Fund process as required

In addition to these actions the NSCOP also identifies the following priorities, relevant to the implementation of the *Time to Move On From Congregated Setting* policy :

- National and Local Consultative Process :Establish a local consultative forum and a number of subgroups including *Time To Move On From Congregated Settings*
- Drive the reform programme through the 6 national working groups, subgroups and related processes.
- Develop as a priority the National Frameworks for implementation of “*A Time To Move On From Congregated Settings*” on standardised basis including support to Chief Officers in the development of Implementation Plans, National Toolkit, and Standard Consultation Process with service users’ families etc. linking with the Head of Operations on planning, capital and other resource requirements for the Development Plan.

8.2 Detailed Actions relating to “Time To Move On” in 2017

The 2017 work plan set out for the *Time To Move On* Subgroup and the members of the HSE Reform Team involved in *Time to Move On* take cognisance of the NSP and NSCOP actions and seek to ensure that we support the completion of the delayed projects in 2016 and the new projects in 2017.

For 2017 a work plan is in place to ensure that we can continue to respond to the operational challenges and can drive forward the implementation of the *Time to Move On From Congregated Setting* policy. This plan will ensure activity at a national level is focussed on supporting providers and that oversight of the implementation of the policy is further enhanced. The work plan consists of 28 specific actions and the full list of the Social Care Disability Reform Team 2017 Work plan and Actions related to the Implementation of *Time To Move On* can be found in Appendix 6.

9. Addressing the Challenges identified in 2016

There is a range of activity scheduled for 2017 to ensure that the current challenges identified are being managed. Much of this work is being delivered as part of the 28 actions in the work plan, but in some cases additional activity is being undertaken to ensure that we are proactively supporting providers as issues emerge. In relation to the challenges identified in 2016 the following specific activity is underway.

9.1 Accommodation Challenges

- Work will continue in close collaboration with the HSE Estates Department and service providers to ensure there is appropriate oversight of the expenditure of capital monies to support individuals to move from the congregated settings identified. Documentation will be developed in 2017 that will support streamlining and consistency in approach to housing issues:
 - Housing Guide - Checklist for property viewing
 - Housing Specifications - equipping lists & procurement processes
 - Guidance on house design -“Template Houses”
- A “Making Homes” work stream will be initiated. This will examine current good practise and produce guidance for providers on the design, adaptation and equipping of homes to meet the needs of people with disabilities and satisfy relevant regulations. The focus will be on enabling and supporting providers to focus on delivering a “home” for individuals rather than a care setting
- The development of the multi-annual profile will support and inform the allocation of the remaining €60million HSE capital Funding. The DHPCLG will support Service Providers to plan in advance of a calendar year in relation to properties and transitions. There will also be a focus on site acquisition or redevelopment and builds rather than acquisition
- Specific work will continue with the DOH and HSE led by the DHPCLG to improve the CAS application process
- Cross departmental work will continue to support implementation of housing policy to positively impact on those individuals moving from congregated settings, and ensure that there is agreement in relation to appropriate expenditure on housing particularly in relation to property values and adaptation costs
- Engagement will continue between HSE and HIQA to maintain a focus on the

agreed priority sites and to ensure that the process of decongregation is appropriately managed in line with the regulations inspected by HIQA.

9.2 Communications

- The Communication Work stream will be developing additional resources to further support Service Providers to share real-life stories and show case the positive outcomes experienced by residents, family and staff when people move to the community. These will include:
 - Easy read version of documents
 - Plain English documents
 - Video stories
 - Newsletters

There will be a focus nationally on tracking the HR issues that are arising to ensure that there is not a duplication of effort and that any solutions are shared where applicable. We will support the shared learning of service providers, through workshops and the development of resources as part of the Implementation Framework.

9.3 Revenue Resource Challenges

Work will continue to drive out the release of SRF for the priority sites to ensure that these projects can achieve their targeted transitions and start to change the model of service being delivered for those moving from the congregated settings.

There will be on-going use of the NDAT data and master data set information to support bids for additional revenue funding that will support individuals to transition and to highlight where blockages are arising and can be linked to revenue funding gaps.

10. Conclusions & Next Steps

By the end of 2016 we had passed the half-way point in terms of the original seven year timeframe that was recommended for the implementation of the *Time To Move On From Congregated Settings* policy. Since 2012 significant progress has been achieved with very little additional resources. It is now recognised that full implementation of the policy will not be achieved by 2019. The *Programme for a Partnership Government* identifies a revised target of achieving a one-third reduction of the numbers remaining in congregated settings by the year 2021, which demonstrate 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.

Over the past 4 years many service providers have made substantial progress which 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.

Housing is the significant step in supporting individuals to move into the community and all the additional capital resources announced and provided during 2016 are an essential “enabler” for the policy. In 2016 and into 2017 it is 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. These include managing individual and family uncertainty, staff concerns and HR issues, revenue funding issues, day to day governance issues and leadership capacity. We have already seen instances of projects being delayed or derailed by these challenges. On this basis, as part of the project action plan process it is strongly recommended that as part of the monitoring of each project, service providers and CHO teams give due regard to these

areas so that issues can be avoided or addressed in a timely manner.

There is evidence from the 2016 Project Action Plans completed by the priority sites that the commitment and momentum towards implementing the policy continues to grow within certain services, but the lack of progress in some locations indicates that there is still some inertia in other locations.

Evidence shows that a commitment to deliver change and a strong partnership approach between the CHO and the local service provider are essential enablers to support the implementation of the policy. Without the support and commitment to the process at a local level from these key stakeholders, the process of transitioning people from the congregated settings can easily stall. The pressure on the residential services in terms of emergency placements and overall bed capacity, alongside the need to deliver services within agreed budgets is acknowledged, but this should not prevent a close collaboration between the CHO and the service provider to ensure that transitions are carefully planned and appropriately supported. Without this planning there is an increased risk that moves will be made without the appropriate level of support or resources, which has the potential to negatively impact on the outcome for the individual, their family, the staff involved as well as damaging the relationship between the stakeholders and undermining support for future decongregation plans.

The HSE Disability 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 to ensure the best outcome for each person that moves. Priorities will include the development 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 From Congregated Settings* Report

Table A1 gives a summary overview of the current status of each of the 31 recommendations in the *Time To Move On From Congregated Settings* report at the end of December 2016.

Table A1: Current Status of Report Recommendations on 31/12/16

| Status of Action | No of actions | Action Reference No |
|-------------------------|----------------------|---|
| Complete | 6 | 1, 2, 3, 7, 9, 20,26 |
| On-going – Advanced | 18 | 6, 8, 10, 11, 12, 13, 14, 15, 17, 18, 19, 21, 22, 23, 25, 28, 29 |
| On-going- Early stages | 7 | 4, 5,16, 24, 27, 30, 31 |
| To be addressed | 0 | none |

In Table A2 , the full details of the 31 report recommendations are given, including the detail of each original recommendation, the status at the end of 2016 and an update on the activity completed and on-going as part of the work to address each recommendation.

Table A2: 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 | 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) 2011-2016 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 <i>Time To Move On</i> 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. |
| 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 (Early) | <p>The historic skill mix in many services includes both direct and non-direct staff and a staffing mix that reflects the medical model of care. Supporting people to move into the community requires 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.</p> <p>A Community Living Transition Plan (CLTP) toolkit was developed and disseminated in 2014 to support services to plan for the transition of people which included identifying the individual supports required to facilitate and sustain a successful transition.</p> <p>An Implementation Framework continues to be developed that will support and guide Service Providers in regard to the key areas that need to be addressed when reconfiguring services. This includes 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.</p> |

| No. | Responsible body | Recommendations | Status | Actions to Date |
|-----|------------------|--|------------------|---|
| 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 (Early) | <p>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:</p> <ul style="list-style-type: none"> • 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. <p>The Implementation Framework continues to be developed to support and guide Service Providers in regard to the key areas that need to be addressed when reconfiguring services, which includes a focus on delivering community inclusion. The Framework will provide guidance on: community capacity building strategies; development of skill set and roles to support community inclusion (Local Area Co-ordinators/ Community Connectors); Communication to promote /develop community inclusion; cross- sectoral protocols etc.</p> |
| 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 | <p>The Transforming Lives” Programme in the Disability Services was established in 2014 under the HSE System Reform Programme. The <i>Time To Move On</i> 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.</p> <p>The National Service Plan 2016 confirmed that new capital resources have been allocated from 2016-2021 to support the transitions from congregated settings and that the Service Reform Fund will also provide some resources for innovative and transitional revenue costs that support the process of de-congregation in 2016-2019.</p> <p>As the provision of residential services, including congregated services is delivered by a multitude of different service providers, the Project Action Plan documentation suite along with a range of additional resources under the Implementation Framework have been put in place to. These are available to support services to develop their own change management plans and ensure the appropriate allocation of resources.</p> |

| No. | Responsible body | Recommendations | Status | Actions to Date |
|-----|------------------|--|----------|--|
| 7 | HSE | <p>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.</p> <p>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.</p> | Complete | <p>Recommendation 5 above also refers.</p> <p>The Community Living Transition Plan Toolkit and Implementation Framework both clearly 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.</p> <p>The revised CAS Guidance in Housing Circular 45/2015 includes specific requirements that will ensure accommodation sourced through this funding mechanism is person centred and in keeping with individual plans.</p> |
| 8 | HSE | <p>All those moving from congregated settings should be provided with dispersed housing in the community, where they may:</p> <ul style="list-style-type: none"> • 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 | On-going | <p>The Community Living Transition Plan Toolkit supports services to identify each person’s preference in terms of their future housing choice.</p> <p>Under the <i>Time To Move On</i> 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.</p> <p>The revised Housing Circular (45/2015) and CAS Call (29/2016) in place now ensures that accommodation sourced through this funding mechanism is now person-centred, dispersed and in keeping with individual plans.</p> <p>Capital resources of €100million have been allocated from 2016-2021 to support the transitions from congregated settings. The HSE at a national and area level will ensure the allocation of capital resources is in keeping with the <i>Time To Move On</i> policy in terms of clustered /dispersed housing and delivery of person centre plans.</p> |
| 9 | HSE | <p>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.</p> | Complete | <p>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</p> <ul style="list-style-type: none"> • 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. • |

| No. | Responsible body | Recommendations | Status | Actions to Date |
|-----|--|--|----------|--|
| 10 | HSE | <p>Supported living arrangements should enable the person to choose to:</p> <ul style="list-style-type: none"> 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 | On-going | <p>The Community Living Transition Plan toolkit supports service providers to identify and develop supports that are person-centred and individualised.</p> <p>Current service provision arrangements can facilitate a combination of shared and individualised supports and this will be further enhanced with the implementation of the <i>New Directions</i> model of Day Services and the development of enhanced community supports.</p> <p>Work has been undertaken by the Disability Service Improvement Team to analyse current funding and service provision to link activity and outputs, cost, quality and outcomes. The HSE in collaboration with the NDA, government departments and other stakeholders continue to examine the applicability of funding and assessment models across the disability sector</p> |
| 11 | HSE | <p>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.</p> | On-going | <p>The Project Action Plan provides guidance for Service Providers in regard to the key areas that need to be addressed when reconfiguring services, which includes a focus on enabling community inclusion.</p> <p>In 2016, Supported Self Directed Living (SSDL) training was delivered to nominated staff that were identified as leaders in their organisation. These staff were trained to enable them to bring about a real and meaningful change in individual's lives.</p> |
| 12 | HSE | <p>Action is required by HSE to strengthen the capacity of community health services to deliver supports to people with disabilities.</p> | On-going | <p>A communication strategy is in place that identifies the need for engagement to ensure the wider community health service can respond to the needs of those moving out of congregated settings and accessing community supports at a local level.</p> <p>Mechanisms for the management or escalation of blockages and issues will be introduced once the new CHO management structures are fully in place. This will further support services to develop local arrangements, where appropriate, and provide a mechanism for regional or national engagement, when required.</p> |
| 13 | HSE & Department of Environment, Heritage and Local Government and local authorities | <p>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.</p> | On-going | <p>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.</p> <p>The disability service providers are working in collaboration with the local authorities, Housing Agency, approved housing bodies and DECLG with regard to addressing the housing needs of people with disabilities. See also Recommendation 18, 19, 20</p> |

| No. | Responsible body | Recommendations | Status | Actions to Date |
|-----|------------------|--|------------------|---|
| 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. | On-going | <p>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.</p> <p>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 (See recommendation 11).</p> |
| 15 | HSE | The individualised supports for people with disabilities should be delivered through a coordinating local structure based on defined HSE catchment areas, within which the full range of supports is available. | On-going | <p>Service providers ensure that in line with the Community Living Transition Plan for each person and their overall service-specific strategic plans for complete de-congregation, there is a co-ordination of services, to ensure the optimal range of supports are provided to people living in the community .</p> <p>Further work to develop local area co-ordination and CHO level planning is required.</p> |
| 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 (Early) | 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 and is informing process undertaken at a local level when negotiating individual service provision. |
| 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. | On-going | <p>The funding for residential services in the non-statutory providers is identified and managed under the Service (Provider Governance) Arrangements.</p> <p>Under these arrangements the HSE ensures that allocated funding is appropriately managed to support the delivery of the agreed quantum/type of services</p> |
| 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. | On-going | <p>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.</p> <p>The <i>Time To Move On</i> working group developed a housing options document in 2016, to capture for providers all the current funding mechanisms and options available for securing housing.</p> |

| No. | Responsible body | Recommendations | Status | Actions to Date |
|-----|--|--|----------|---|
| 19 | HSE and Government | <p>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</p> <p>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.</p> | On-going | <p>In 2013 -15, €1million was made available by the DOH through the DELCG for leasing under the social housing model, to support the housing needs of people leaving institutions and to enable housing authorities to provide some new homes in the community for people with disabilities. At the end of each year any unspent portion of this funding has been allocated towards innovative projects or the purchase and /or adaptation of properties that support a number of individuals to transition.</p> <p>An additional €4million was made available at the end of 2014 by the DELCG for the purchase of properties to support the transition of people in line with the NHSPB. This was administered by the Housing Agency in collaboration with the HSE, service providers, approved housing bodies and local authorities.</p> <p>The National Service Plan 2016 confirmed that new capital resources of €100 million will be allocated from 2016-2021 to support the transitions from congregated settings. This recognizes that in some instances purpose built housing will be required. In 2016, €20million was allocated to priority projects for housing for 165 residents.</p> <p>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 <i>Time To Move On</i> policy, National Financial Regulations and relevant Capital Management processes</p> |
| 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 DOH, DELCG, 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. |

| No. | Responsible body | Recommendations | Status | Actions to Date |
|-----|--|--|------------------|--|
| 21 | HSE | <p>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.</p> <p>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.</p> | On-going | <p>The <i>Community Living Transition Plan</i> Toolkit and the <i>Housing Options</i> document supports services to identify each person's preference in terms of their future housing choice.</p> <p>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 is drafting their own "Strategic Plan for the delivery of the National Housing Strategy for People with Disabilities " ,which identifies all the current and future housing need in their area, including individuals resident in congregated settings.</p> <p>The Local Authority Housing and Disability Groups are currently in the process of submitting their draft plans to the National group for collation</p> |
| 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. | On-going | 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 NHSPD groups. |
| 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 | On-going | <p>There are a number of known complexities which have impacted the achievability of this timeframe for some services including: capital funding, individual choice; living arrangements and locations; transitional and on-going funding; the future role of staff, training and skill mix, the development and sustainability of community linkages, supports and engagement.</p> <p>In the Programme for a Partnership Government, the revised target of a one third reduction by 2021 is stated.</p> |
| 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. | On-going (Early) | <p>The HSE established a National Implementation Group in 2011 to oversee the implementation of the policy. Below this, Regional and Local Implementation Teams as subgroups of the Regional and Local Disability Consultative Fora were established to support the roll out of implementation.</p> <p>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" (Congregated Settings) Workgroup will be rolled out in due course to support the implementation of the policy in the future.</p> <p>The HSE through these structures will support services to develop their own change management plans using the Implementation Framework, which will identify resource and service specific issues</p> |

| No. | Responsible body | Recommendations | Status | Actions to Date |
|-----|------------------|--|------------------|--|
| 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. | On-going | <p>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 services to more socially inclusive settings would be achieved.</p> <p>There was a focus on supporting the priority sites to develop and deliver plans early in 2016, but work was also undertaken to support the non-priority sites to develop their plans using the template documentation, later in the year. All priority sites submitted plans that were reviewed by the National Social Care division and CHO team locally.</p> |
| 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 | <p>The HSE established a National Implementation Group in 2011 to oversee the implementation of the policy. The work of this group and its subgroups included the dissemination of Key Learning from projects that have completed transition.</p> <p>These projects include samples of both projects funded by Genio (accelerated learning sites) and any other projects that have completed the transition process. The key learning from projects has been forwarded to service providers to guide and assist them in the development of plans and the transition process. The National Congregated Settings Workgroup is continuing to gather information from services that have completed transitions to enable on-going shared learning.</p> <p>In 2016, a further cohort of priority accelerated sites were identified and supported to develop transition plans for defined and targeted groups of individuals within their services. Capital funding was made available to support these proposals and dedicated a SRF funding stream was also put in place</p> |
| 27 | HSE | A range of new funding streams should be brought together in a Congregated Settings Fund | On-going (Early) | See Recommendation No 6, 8, 19 and 29, where the current various funding streams supporting the implementation of the Time To Move On From Congregated Settings policy are discussed. |

| No. | Responsible body | Recommendations | Status | Actions to Date |
|-----|------------------|--|------------------|--|
| 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. | On-going | <p>Projects funded through the Genio Trust have undergone a comprehensive evaluation, which has provided documented findings and learning for the sector, see Recommendation 26.</p> <p>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.</p> <p>The Project Action plan documentation provides a framework for the evaluation of projects against key themes and work strands. During 2016 this was introduced and an Oversight group was established to evaluate plans and provide feedback.</p> |
| 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. | On-going | <p>Resources have been made available through Next Steps and other initiatives to support this change programme.</p> <p>Additional transitional revenue and capital resources is being made available and 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.</p> <p>Under the Dormant Accounts initiative, POBAL working with the DOH and HSE sought submissions for projects that would deliver Local Area Co- Ordination initiatives in keeping with the “Transforming Lives” programme. The successful projects were resourced in 2016</p> |
| 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. | On-going (Early) | <p>Currently, 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.</p> <p>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.</p> <p>The HSE, as part of the six steps Safeguarding Programme launched in December 2014, is due to establish a Volunteer Advocacy Programme in addition to the advocacy supports available through NAS.</p> <p>The HSE is supporting Inclusion Ireland to develop family forums in a number of</p> |

| | | | | <p>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.</p> <p>During 2016, the Head of the National Advocacy Service met with service providers at a national event to provide guidance on the appropriate use of their service.</p> |
|-----|------------------|---|------------------|---|
| No. | Responsible body | Recommendations | Status | Actions to Date |
| 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 | On-going (Early) | <p>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.</p> <p>An expert working group, led by the Disability Federation of Ireland is currently carrying out a review of all 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.</p> <p>In 2017, a review will commence to examine other large (10 or more residents) residential services for people with disabilities that were not captured as part of the original report.</p> |

Appendix 2: *Time to Move On* Subgroup Membership in 2016

Suzanne Moloney, HSE National Disability Reform Team (Chair)

Gabrielle O’Keeffe, HSE Cork & Kerry Community Health Organisation

PJ Cleere, Disability Federation of Ireland, DFI representative

Jim Winters, *Inclusion Ireland representative (left group in March 2016)*

Mark O’Connor, Inclusion Ireland representative (joined May 2016)

Brian Dowling, *Department of Health representative (left group in January 2016)*

Claire Collins, Department of Health (joined March 2016)

Patricia Curran, Department of Housing, Planning, Community and Local Government representative

Martina Larkin, *Cheshire Ireland, NFPBA representative (left group October 2016)*

Majella Grainger, Cheshire Ireland, NFPBA representative (joined November 2016)

Brendan Broderick, Muiriosa Foundation & National Federation of Voluntary Bodies

Anna Cunniffe, National Disability Authority representative

Clare Dempsey, St. John of God representative

Breda O’Neill, St. Margaret’s Donnybrook & National Federation of Voluntary Bodies

Alison Ryan, HSE Project Support Office

Appendix 3: 2015 Admissions /Re-admissions Update

There were 41 admissions/readmissions to congregated settings during 2015. The 2015 Progress Report on the implementation of Time to Move on from Congregated Settings provides an overview of the age profiles, levels of disability of people admitted and the type of placement to which people were admitted.

In June of 2017 a brief questionnaire was circulated to request an update on the current residential status of the people admitted/readmitted during 2015. The information returned forms the basis of this update.

The main reasons for the admissions are as follows:

- 10 people were admitted due to changing / deteriorating health needs
- 8 emergency admissions – in two instances principal carer passed away.
- 5 people were admitted from community residential services
- 7 people in respite placements were converted to admissions
- 2 people were referred by the HSE, one in unsuitable living arrangement and one post stroke
- 1 person requested to return to the congregated service
- 2 people have specific housing requirements

No specific reason was given for 6 admissions but of the six - 3 people have transitioned, 2 require a multidisciplinary assessment and the remaining person moved within the existing service.

Information was also requested on the current residential status of the people admitted. The information received confirms that:

- 8 people have transitioned
- 3 of the people readmitted during 2015 have passed away
- 6 people were readmitted due to deteriorating health needs
- 14 people admitted have a transition plan
- 7 people have no specific transition plan. Of the 7:
 - 5 people were admitted due to deteriorating health needs
 - 1 person was admitted following the death of principal carer
 - 1 person admitted post stroke
- 2 people will have a full MDT to determine future plan

Appendix 4: Profile of Congregated Settings remaining at 31/12/2016

| Service Providers and Locations in CHO Area 1 | | | |
|---|---|----------------------------------|--|
| Service Provider | Service Areas Identified in CHO by Provider | No of residents as at 31/12/2016 | No of Centres/Units/Campus's within this Service & approximate locations |
| Cheshire Ireland | Cheshire Letterkenny | 11 | 1 centre, Letterkenny , Co Donegal |
| | Cheshire Sligo | 7 | 1 centre, Sligo town |
| HSE | HSE Donegal - | 12 | 1 centre, Bundoran , Co Donegal |
| | HSE Donegal - | 16 | 1 centre, Carndonagh, Co Donegal |
| | HSE Donegal - Donegal | 9 | 1 centre Kilymard , Co Donegal |
| | HSE Donegal - | 6 | 1 centre, Stranorlar, Co Donegal |
| | HSE Sligo - | 43 | 1 centre, Collooney, Co. Sligo |
| | HSE Sligo Cregg House | 95 | 20 centres on a campus , Ballincar, Co Sligo |
| 2 providers | 8 Service Areas | 199 | 27 Units/Centre |

| Service Providers and Locations in CHO Area 2 | | | |
|---|---|----------------------------------|--|
| Service Provider | Service Areas Identified in CHO by Provider | No of residents as at 31/12/2016 | No of Centres/Units/Campus's within this Service & approximate locations |
| Brothers of Charity Galway | Brothers of Charity Galway , John Paul Centre | 22 | 4 centres on a 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 | 87 | 17 centres on a campus, Swinford, Co Mayo |
| 3 providers | 4 Service Areas | 125 | 23 Units/Centre |

Service Providers and Locations in CHO Area 3

| Service Provider | Service Areas Identified in CHO by Provider | No of residents as at 31/12/2016 | No of Centres/Units/Campus's within this Service & approximate locations |
|------------------------------|--|---|---|
| Brothers of Charity Limerick | Brothers of Charity, Limerick | 77 | 16 centres on a campus, Bawnmore, Limerick City |
| Cheshire Ireland | Cheshire Limerick | 18 | 1 centre ,Newcastle-West , Co Limerick |
| Daughters of Charity | Daughters of Charity, St Vincent's Centre | 119 | 22 centres on a campus , Lisnagry, Co. Limerick |
| | Daughters of Charity, St Anne's Centre | 28 | 4 centres on a campus, Roscrea, Co Tipperary |
| 3 providers | 4 Service Areas | 242 | 43 Units/Centres |

| Service Providers and Locations in CHO Area 4 | | | |
|---|---|----------------------------------|---|
| Service Provider | Service Areas Identified in CHO by Provider | No of residents as at 31/12/2016 | No of Centres/Units/Campus's within this Service & approximate locations |
| Brothers of Charity Southern | Brothers of Charity, Upton Campus | 28 | 6 centres on a campus, Upton, Co. Cork |
| | Brothers of Charity, Lota Campus | 40 | 12 centres on a campus, Glanmire Co. Cork |
| Cheshire Ireland | Cheshire, St Laurence, Cork | 17 | 1 centre and apartments on a campus Glanmire, Co. Cork. |
| | Cheshire, Killarney | 10 | Apartment complex, Killarney, Co. Kerry. |
| Cork Association for Autism | Cork Association for Autism | 13 | 8 centres (including some apartments / cottages) on a campus Carrigtwohill, Co Cork |
| HSE | HSE Kerry | 21 | 2 centres (adjoining), Killarney |
| | HSE Cork St. Raphael's Centre | 74 | 10 centres, Youghal, Co. Cork. 4 on Campus A ; 5 on Campus B; 1 other separate centre |
| COPE Foundation | COPE Foundation | 347 | 9 centres on Campus A, Montenotte, Cork |
| | | | 3 centres on Campus B, Montenotte, Cork |
| | | | 7 centres on a Campus, Hollyhill Cork City |
| | | | 13 centres in Cork City locations : Togher (2), Tivoli, Glasheen (2), Deerpark (cluster of 7), Turners Cross |
| | | | 13 centres in County Cork locations: Middleton, Skibbereen, Macroom, Fermoy, Kanturk, Ballincollig , Clonakilty (3) , Bandon (2), Mallow (2) |
| St John of Gods | St John of God, Kerry Services, Beaufort | 77 | 11 centres on a campus, Beaufort, Co. Kerry. |
| St Vincent's Centre | St Vincent's Centre | 31 | 1 centre on a campus ,Cork City |
| 7 providers | 11 Service Areas | 658 | 97 Units/Centres |

| Service Providers and Locations in CHO Area 5 | | | |
|--|--|---|--|
| Service Provider | Service Areas Identified in CHO by Provider | No of residents as at 31/12/2016 | No. of Centres/Units/Campus's within this Service & approximate locations |
| Brothers of Charity, South | Brothers of Charity, Waterford | 11 | 1 centre, Belmont Park, Waterford |
| Carriglea Cairdre Services | Carriglea Cairdre Services | 37 | 7 centres on a campus, Dungarvan, Co. Waterford |
| Cheshire Ireland | Cheshire Tullow | 9 | 1 centre and apartment complex ,Tullow Co. Carlow |
| HSE | HSE Wexford Residential IDS (WRIDS) | 32 | 3 centres in Co Wexford locations: Wexford (1) ,Enniscorthy (2) |
| St. Patricks Centre, Kilkenny | St. Patricks Centre Kilkenny | 85 | 1 Campus with 2 centres, one of which has multiple units , Kilkenny City |
| 5 providers | 5 Service Areas | 174 | 15 Units\Centres |

| Service Providers and Locations in CHO Area 6 | | | |
|--|--|---|---|
| Service Provider | Service Areas Identified in CHO by Provider | No of residents as at 31/12/2016 | No of Centres/Units/Campus's within this Service & approximate locations |
| Cheshire Ireland | Cheshire Monkstown | 10 | 1 centre Monkstown, Co. Dublin |
| | Cheshire Shillelagh | 22 | 1 centre, Shillelagh, Co. Wicklow |
| Children's Sunshine Home | Children's Sunshine Home | 10 | 1 centre, Foxrock, Dublin |
| HSE | HSE Southside IDS, Aisling House | 14 | 2 adjacent centres, Maynooth Co. Kildare. |
| | HSE Southside IDS, Hawthorns | 23 | 5 centres in a cluster , Stillorgan, Co. Dublin |
| St John of Gods | St John of Gods Carmona | 9 | 1 centre on a campus, Bray. Co. Wicklow |
| St Margaret's Centre | St Margaret's, Donnybrook | 16 | 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 a cluster, Ashford, Co. Wicklow |
| | Sunbeam, Valleyview | 15 | 2 adjacent centres, Rathdrum, Co. Wicklow |
| 6 providers | 11 Service Areas | 142 | 21 Units\Centres |

| Service Providers and Locations in CHO Area 7 | | | |
|---|--|----------------------------------|--|
| Service Provider | Service Areas Identified in CHO by Provider | No of residents as at 31/12/2016 | No of Centres/Units/Campus's within this Service & approximate locations |
| Cheeverstown | Cheeverstown House | 65 | 14 centres on a campus, Templeogue, Dublin |
| Peamount Healthcare | Peamount Healthcare | 79 | 17 centres on a campus, Newcastle, Co. Dublin |
| St John of God Services | St John of God, St Raphael's, Celbridge | 118 | 14 centres on a campus, Celbridge, Co. Kildare |
| | St John of God, Islandbridge | 13 | 1 centre, Islandbridge, Dublin |
| Stewarts Care | Stewarts Care | 169 | 25 centres on a campus, Palmerstown, Dublin |
| 4 providers | 5 Service Areas | 444 | 71 Units/Centres |
| Service Providers and Locations in CHO Area 8 | | | |
| Service Provider | Service Areas Identified in CHO by Provider | No of residents as at 31/12/2016 | No of Centres/Units/Campus's within this Service & approximate locations |
| Muiriosa Foundation | Muiriosa Foundation Moore Abbey | 22 | 4 centres on a campus Monasterevin, Co. Kildare |
| | Muiriosa Foundation, St. Marys Centre | 5 | 1 unit on a campus, Delvin Co Westmeath |
| St. John of God Services | St. John of God Service, North East – St Mary's Campus | 103 | 15 centres on a campus, Drumcar, Co Louth |
| 2 providers | 3 Service Areas | 130 | 21 Units/Centres |

Service Providers and Locations in CHO Area 9

| Service Provider | Service Areas Identified in CHO by Provider | No of residents as at 31/12/2016 | No of Centres/Units/Campus's within this Service & approximate locations |
|----------------------------|--|---|---|
| Cheshire Ireland | Cheshire, Cara | 14 | 1 centre, Phoenix Park, Dublin |
| Daughters of Charity | Daughters of Charity, St. | 102 | 16 centres on a campus, Clonsilla, Dublin |
| | Daughters of Charity, St. Louise's Centre | 53 | 10 centres on a campus, Glenmaroon, Dublin |
| | Daughters of Charity, St. Rosalie's | 15 | 1 centre, Portmarnock, Co. Dublin. |
| | Daughters of Charity, St. Vincent's Centre | 78 | 13 centres on a campus, Navan Road, Dublin. |
| HSE | HSE, Cuan Aoibheann | 11 | 1 centre on a campus , Phoenix park, Dublin |
| | HSE, St. Josephs IDS | 14 | 16 centres on a campus, Donabate Co. |
| | | | 1 campus with multiple units , Oldtown, Co. Dublin |
| 1 centre, Lusk , Co Dublin | | | |
| St. Michael's House | St. Michael's House, Baldoyle | 15 | 1 centre , Baldoyle, Dublin |
| | St. Michael's House, | 39 | 6 centres on a campus, Ballymun, Dublin |
| 4 providers | 9 Service Areas | 465 | 73 Centres /Units |
| | | | |
| Total | 60 service Areas | 2579 | 391 Centres/ Units |

Appendix 5: Details about a Congregated Settings that closed during 2016

Grove House

Located on St Mary's Health Campus in Cork city, Grove House was originally a designated centre under the Mental Health Services, providing long term residential care and respite to adults with a dual diagnosis of mental health and intellectual disability support needs. The centre was de-designated in 2005 to become a disability residential service, for adults with intellectual disabilities. From 2005 onwards, there continued to be a steady demand for residential and respite placements in the Grove House service from across the region, as the service was located close to the acute services, there was a medical model of staffing with RNID, RNMH and RGN nurses all working in the service and there was regular on-site support from a Consultant Psychiatrist specialising in ID and a Medical Officer.

In 2013 in line with best practice the HSE developed a business plan in 2013 to commence the process of preparing and planning for the decongregation of Grove House that would support all the residents to transition to homes in the community in line with national policy.

In line with the plan, the HSE established a partnership with COPE Foundation a Cork-based service provider with significant experience in providing high quality services to people with intellectual disabilities. COPE deployed a team who undertook to develop a comprehensive assessment of the needs of each resident to inform and assist in planning for their transitions.

Grove House was closed to admissions in 2013 to facilitate the transition to the new model of service delivery. Active collaboration commenced with all the relevant stakeholders: the residents, their families, the county council, approved housing bodies and other service providers to secure alternative community residential placements.

Initially progress was slow with less than five residents moved in the first year. The HSE acknowledged that the service was no longer fit for purpose and worked collaboratively with HIQA to close Grove House on a phased basis. This provided time to ensure that appropriate alternative placements were identified, which best suited each resident's individual needs and choice. All decisions were made in consultation with the residents and their families.

To support the phased closure in 2015 a full time Director of Nursing and additional experienced nurse managers were recruited. Staff worked with residents and their families

to improve resident communications and access to activities e.g. supporting individual choices at mealtimes, providing additional speech and language therapy sessions and reviewing residents' care plans. Additional advocacy supports were provided to ensure resident's voices were heard and that residents with communication problems were appropriately supported.

By March 2016 all the residents from Grove House were transitioned to appropriate accommodation with other providers. In total nine other service providers accommodated the residents from Grove House with arrangements that ranged from bespoke single person arrangements to small community group homes. Some individuals moved to newly developed services, whilst others moved to vacant placements that arose in existing community facilities. Some residents moved in with friends, whilst others moved on their own to share with new housemates or live alone. Due to the complexity and/or changing needs of some of the residents, a number of individuals were supported to transition to specialist services including centres that deliver nursing home type care for people with disabilities and services that provide intensive support for those with behaviours that challenge.

Appendix 6: 2017 Work Plan Actions

Oversight of Activity & Learning for 2016

- Compile data on all 2016 activity and status and activity of congregated settings
- Complete annual progress report on 2016 activity

Progress Housing Solutions

- Complete compilation of data from providers to identify housing solutions required 2017-2021
- Finalise recommendations for multi-annual allocation of Capital Funding 2018-2021
- Quarterly meetings with Estates to progress housing through HSE Capital 2016 & 2017
- Quarterly meetings as part of National Housing Strategy for People with Disabilities Steering subgroup to progress housing solutions

Support Communication and Stakeholder Engagement

- Develop material to support implementation of the 'Time to Move On' Communication Strategy
- Compile data from providers on status of local communication plans and supporting documentation
- Develop further guidance document including templates for local supporting documentation
- Develop easy read material to support communication of the policy

Frameworks and Guidance to support Policy Implementation

- Review and update Community Living Planning Toolkit, in line with Aras Attracta report
- Complete proposal for development of HSE held and managed repository of new policies and procedures developed specifically to support transitions into the community
- Commence review to develop recommendations in relation to development/retention of specific specialist services
- Complete review on specific specialist residential services & furnish recommendations report for approval
- Develop guidance resources on key work streams as part of on-going development of an Implementation Framework

Site Specific Implementation Plans

- Host event to support development of project action plans for 2017 priority sites

- Support the review and update of project actions plans from 2016 priority sites through CHO teams
- Support development of project actions plans for all new priority settings in 2017 through CHO teams
- Support development of project actions plans by all congregated settings through CHO
- In collaboration with Operations team, review project action plans for all 2017 priority settings and provide feedback to CHO and providers

Site Engagement

- Identify and agree priority sites for engagement in 2017 and schedule site visits
- Complete site visits. A key deliverable will be to ensure there is an understanding of how people should be engaged with regarding the transition to community settings.

Learning Events

- Develop and set schedule of at least 2 workshops, in consultation with providers that will target specific themes/areas of concern in workshop format
 - Deliver 1st Workshop
 - Deliver 2nd Workshop
- Host one national 'Time to Move On ' Learning Event during 2017

CHO Implementation structures

- Support development of CHO structures to drive policy implementation at CHO level and improve links to National Time to Move on Subgroup
- Engage with key members of each CHO team (as part of Reform Team) to agree annual priorities, targets and communication/reporting pathways