Key messages

Áras Attracta Swinford Review Group

July 2016

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Aras Attracta Swinford Review Group Members

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Background to the Áras Attracta review

Following the broadcast of the RTÉ *Prime Time Investigates* programme 'Inside Bungalow 3' in December 2014, the HSE commissioned an independent review of the quality of care at Áras Attracta. The **Áras Attracta Swinford Review Group** was appointed within a month of the broadcast of 'Inside Bungalow 3', and its terms of reference were agreed on 7 January 2015.

The Áras Attracta Swinford Review Group consists of specialists in the fields of intellectual disability, the protection of vulnerable people, and change management; and the group was supported by people with expertise in the areas of disability, ageing, and social research. The key objectives of the Review Group in carrying out our work were:

- To review the programme of work already under way at Áras Attracta on foot of reports from HIQA and the HSE, to establish the effectiveness of this work, to identify any gaps in service, and to make recommendations for further service improvements.
- To identify any issues of immediate concern in relation to the care and safety of the residents, and to bring these to the attention of the HSE.
- To identify any factors that might have caused or contributed to the events shown in the *Prime Time* programme.
- To recommend actions to reduce or eliminate the risk of events such as those shown in the *Prime Time* programme happening again.
- To recommend actions to ensure that the learning from the Review Group is reflected and promoted throughout the residential care sector.

1.1 About Áras Attracta

Áras Attracta is a HSE-run residential centre located in Swinford, a small rural town in Co. Mayo. At the beginning of this review there were 96 men and women with intellectual disabilities living in Áras Attracta. It is located on a 13 hectare site and comprises 29 buildings, including 16 bungalows ranging from 200 to 400 square metres in size, an administration block and a suite of offices, training rooms, a swimming pool and gym, a Snoezelen, a prayer room, a day centre, a canteen, and lots of open space. Over 300 people work at Áras Attracta, including nurses, health and social care assistants, social care workers, allied health professionals, administrative staff, service staff, and others. A number of contracts for service also exist – for example, cleaning, catering, transport, security, hairdressing and laundry (except personal laundry).

Where residents came from

Opened in 1988, Áras Attracta was a specially designed campus-style facility developed to look after adults with intellectual disabilities. Approximately a third of residents previously resided in their own homes, about a third were transferred from St Mary's Psychiatric Hospital in Castlebar, and about a third came from other institutions, residential centres or psychiatric hospitals.

When residents arrived

Roughly two thirds of the current Áras Attracta residents arrived before 1993. The largest intake was in 1992 following the closure of St Mary's Castlebar. Only one or two new residents have arrived in most years since 1992.

Gender and age profile of residents

Men make up 62 per cent and women make up 38 per cent of residents.

Many of the people living in Áras Attracta are now older people, with more than half being over 60.

1.2 Legislative and policy context

The legislative framework, policy context and general thinking about the care and support of people with intellectual disabilities has changed since Áras Attracta was established in the late 1980s Even at that time, questions were beginning to be raised internationally as to whether 'congregated settings' were the best place for people with disabilities to live, with increasing emphasis being placed on community inclusion for people with disabilities.

Among the more important pieces of legislation relating to people with disabilities are the *Education Act 1998*, the *Equality Act 2004*, the *Health Act 2004*, the *Disability Act 2005*, the *Citizens Information Act 2007* and the *Assisted Decision-Making (Capacity) Act 2015*.

The more important policy reports relating to people with disabilities are:

- The Education Act 1998 provides for the education of every person in the state including any person with a disability or special education need.
- Health Service Executive, 2011. Time to move on from congregated settings: a strategy for community inclusion. Dublin: Health Service Executive.
- Health Service Executive, 2012. New directions: review of HSE day services and implementation plan 2012–2016 – personal support service for adults with disabilities.
- Department of Health, 2012. Value for money and policy review of disability services in Ireland. Dublin: Dept. of Health.

Each of these is described briefly below.

Transforming Lives

Transforming Lives – the programme to implement recommendations of the *Value for money and policy review of disability services in Ireland* (Department of Health, 2012) is an evaluation of the effectiveness and efficiency of disability services wholly or partly funded by the HSE in the statutory and non-statutory sectors. The key message from the review is the necessity to move from group-based service delivery towards a model of person-centred and individually chosen supports.

As part of the evaluation, an Expert Reference Group on Disability Policy was established to conduct a policy review, and from this Group's public consultation on existing services what emerged was that people wanted 'flexible supports to suit individual needs, to use local services, do ordinary things in ordinary places, with more opportunities for families to play their part in supporting their family members'. On reviewing existing services the Expert Group found little evidence of individual service provision; instead they found that there was a lack of standardised needs assessment, and that provision was largely based in groups.

Time to move on

The key principle of the HSE's *Time to move on* report is that all housing arrangements for people moving from congregated settings should be in ordinary neighbourhoods in the community with individualised supports tailored to meet the residents' particular needs and wishes.

As part of the implementation of this strategy, €1 million was transferred to the Department of the Environment, Community and Local Government (DCELG) from the Department of Health in 2013–2014 to provide housing for up to 150 people leaving disability or mental health institutions. In 2015, a further €1 million was allocated to DCELG to continue this process.

New directions

New directions is the HSE's national guidance framework for day programmes of personal support services for adults with disabilities. It proposes the development of a person-centred individualised planning approach within a quality assurance framework. The focus is on the enhancement of the capacity of people and recognition of the diversity of their needs – with a view to delivering better outcomes and better value for money.

1.3 The local context in 2015

In addition to the policy and legislative landscape described above, a number of other important local factors influenced the conduct of the work of the Review Group.

- At the time the Review Group embarked on its work, An Garda Síochána was still in the process of undertaking its investigations. For that reason and for fear of evidence contamination, the Review Group could not visit Áras Attracta until early February 2015.
- Changes in personnel at senior management level in Áras Attracta had resulted in an interim arrangement whereby the acting person in charge was on secondment from another service for a defined period which ended in May 2015. A new Person in Charge/Director of Services subsequently took up post in mid-July 2015.
- When the Review Group started its work, Áras Attracta was regarded as one single centre; however, during 2015 it was reorganised into three designated centres:
 - Centre 1 provides services to residents with intellectual disability with complex health needs and high physical dependency
 - Centre 2 supports residents with intellectual disability and behaviours that challenge
 - Centre 3 provides support to residents with intellectual disability and medium levels of dependency.
- Resulting from the reorganisation of the large centre into three smaller ones, three new nurse managers were recruited at Clinical Nurse Manager level 3 to manage the newly configured centres. These new members of staff took up their posts in autumn 2015.
- During the course of 2015, HIQA had carried out a further five inspections in Áras Attracta, some announced and some unannounced. One of these inspections led to a Notice of Proposal to Cancel Registration in August 2015 unless immediate changes were made.
- Changes have also taken place in the HSE at management level, with the introduction of the new Chief Officer post. This post covers the counties of Galway, Mayo and Roscommon, and carries responsibility for facilities such as Áras Attracta.
- During the course of 2015, a substantial staff training programme was initiated in Áras Attracta covering topics such as adult protection and managing behaviours that challenge.
- The American Association of Intellectual and Developmental Disabilities (AAIDD) was commissioned by the HSE to undertake an assessment of the support needs of all individuals in Áras Attracta; it carried out this work in November and December 2015.
- A Family Forum was developed in collaboration with Inclusion Ireland in September 2015. It is chaired by a family member and will play an important part in the advocacy support for families and residents.

All of the events and changes outlined above have combined to create a situation of on-going flux, change, and a degree of uncertainty for residents, relatives, and staff alike. In addition they impacted on the work of the Review Group, as the context for our work was constantly changing.

The Review Group acknowledges that our work impacted on this changing environment and placed some extra demands on residents, their relatives, and staff.

Overall much of the change taking place has created a good foundation for developments for all involved in Áras Attracta.

1.4 The Review Group's approach

As a Review Group, we had a clear vision in conducting our work. We took a person-centred approach that looked at the service from the perspective of the people who live there. This principle guided how we consulted with residents, explained their day-to-day lives and measured their quality of life. It also guided how we reviewed the practices and procedures in all bungalows and units.

Throughout the report we have used the term 'resident' to refer to the people living in Áras Attracta, though we do not see this term applying as people move into community settings.

The approach of the Review Group was underpinned by the following further principles:

- The right of the residents, families, staff, and managers to be treated with respect and courtesy'
- The right of residents to privacy and confidentiality (unless a person's safety is in jeopardy)'
- The right of each resident to be appreciated as a unique and valued person.
- The right of every person to due process, and natural and constitutional justice.

We took a range of approaches to ensure that we could meet our key objectives. These are summarised here and are more fully detailed in later chapters.

Reviewing work already under way

At the time the Review Group began its work, Áras Attracta had already been the subject of a substantial number of audits and reviews, of internal and external inspections, and also of a number of HIQA inspections. All of these had resulted in many recommendations.

We decided to analyse all of these recommendations up to the cut-off point of January 2015, and issued a management review questionnaire to both the senior management of the centre (as it was at that time), and the nurse manager of each bungalow and unit.

This management review questionnaire was reissued some six months later to afford senior management and staff the opportunity to indicate any changes or improvements that had taken place in the intervening period. However, in light of staff changes the two sets of management review questionnaires were not truly comparable.

Identifying issues of immediate concern

The Review Group maintained communication with the HSE throughout the period of the review and areas of concern were brought to the HSE's attention as appropriate. For example, it emerged in the course of the review that no person-centred assessments had been carried out for residents for quite a long time, and that there was a need to develop a rights-based/social model for the support of all residents. The Review Group is aware that individual assessments of all residents in Áras Attracta were completed in December 2015 and inform the individual care plans for all residents.

In addition to recommending the assessment of each resident, the Review Group recommended that the governance of the service should be strengthened by two short-term appointments to facilitate the transfer of residents to community settings. These were to form a new Innovative Community Settings Transfer Unit. The Review Group is aware that transition co-ordinators are now in place, engaging with all stakeholders in order to progress transition to community living.

A staff member raised a number of historical concerns which were referred to senior management in Áras Attracta to ensure that the issues causing concern were not evident in the current services. The Review Group was assured that monitoring arrangements have been put in place in relation to this.

We also recommended the establishment of a Strategic Advisory Group for Áras Attracta whose role would be to:

- Take a long-term view of the support needs of all residents and put appropriate plans in place.
- Provide strategic vision and a guiding framework for the development of services in the community.
- Provide advisory support to the management team.
- Ensure integration with national policies and funding opportunities.

The proposed composition of the Group was:

- 1. An independent industry/commerce representative with change management experience (Chair).
- 2. The Head of Social Care, CHO Area.
- 3. A HSE Representative.
- 4. Non-HSE Task Force members (two). The HSE accepted this recommendation and a Strategic Advisory Group consisting of a small senior group of experts, to support the implementation of the change programme, has been established.

Identifying causal and contributory factors

In seeking to identify what were the key factors that might have caused or contributed to the events shown in the Prime Time programme we took a number or approaches, including:

- Consultations with residents, in which we listened to their views about what they thought about their circumstances in Áras Attracta and what changes they would like to see.
- A study of 'a day in the life' of three residents, in which our main purpose was to come to an understanding of the day-to-day realities in Áras Attracta.
- A survey of the quality of life of a representative sample of residents this presented the findings of an independent survey that sought to measure the quality of life of residents of Áras Attracta in a systematic way..
- Group consultations and some private interviews with relatives, followed by an anonymous questionnaire – which helped us gain an understanding of what relatives thought of services at Áras Attracta and what they felt might be the best ways to improve the quality of service and prevent any abuse of residents.
- Group consultations with a number of staff members, followed by an anonymous questionnaire – in which we sought the views of staff members about their experience of working in Áras Attracta, and about how we can ensure that residents are safe and protected, and how they can realise their full potential.
- A management review questionnaire for senior management and local managers – the purpose of these was to establish the extent to which recommendations from the various reviews and inspections have been implemented to date.
- A person-focused assurance framework that we used to present a profile of Áras Attracta and to explore its organisational and management supports and practices across three broad thematic areas.

Testing our results

Having completed the tasks and activities outlined above, the Review Group invited residents, relatives, staff and management to meetings to receive feedback on the outcome of our work. This feedback was provided in Áras Attracta over a two-day period at which reports from the activities undertaken were presented by members of the Group and by the specialist consultants. On completion of the presentations there was time set aside for discussion. The purpose of this was to seek to eliminate any errors or omissions in our assessment and findings regarding the quality of care and support being provided to residents. Another reason for adopting this approach was to give all participants an early indication of the contents of the report which was to be produced.

Actions to reduce or eliminate risk

In the course of our work, we identified a range of deficits in Áras Attracta and the actions required to reduce the risk of abuse occurring – see pp.13–14.

Identification of key initiatives

The Áras Attracta Swinford Review Group has identified thirteen key initiatives that it recommends the HSE take in the coming twelve months to improve the quality of lives of people living in congregated settings in Ireland. We have also developed an action plan for all congregated settings to help ensure that individuals live in appropriate settings in the community – see pp.15–16.

2

Where we go from here

2.1 A compelling case for change

In the course of its work, it has become increasingly clear to the Review Group that there is a compelling case for change in the way service is delivered at Áras Attracta. Change is also required at a national (HSE) level and across the disability sector, particularly in light of national policy on the move to non-congregated settings.

At an early stage it was identified that every person living in Áras Attracta should have their needs assessed and their support requirements identified. This work, commissioned by the HSE and undertaken by the American Association on Intellectual and Developmental Disabilities (AAIDD) in late autumn 2015, has now been completed. The residents who are ready to move now to a non-institutional setting in the community must be supported to do so without delay. At the same time the Review Group is cognisant that the quality of life must be enhanced for those who remain in Áras Attracta until they too can move.

The learning

The Review Group wanted, above all, to focus on the perspective of people living in Áras Attracta, and to come to an understanding of what daily life is like for them. It was found that they were mostly positive about living in Áras Attracta, they felt supported by staff and most of them had some contact with their families but would like more activities, and to get out more often. The things that mattered most were to feel safe, be respected, have privacy and meet their friends.

However, these relatively positive accounts must be placed in the context that Áras Attracta is the world that they know. As such their expectations, hopes and aspirations are very much limited by the horizons of that world – a congregated setting.

The *day in the life* narratives present a picture of life in Áras Attracta that is characterised by inactivity, lack of stimulation, and dependency on the support of staff for many of the things that most people take for granted. Residents have little opportunity to realise their potential to live the rich and satisfying lives that they have a right to aspire to.

The quality of life survey results are also of real concern. The average number of personal outcomes scored as *fully present* for the sample of people in Áras Attracta was very low and compared poorly with the National Survey findings, which was conducted in 2007.

The engagement with relatives highlights that many have confidence in the services in Áras Attracta. Notwithstanding this, other relatives share common concerns with regard to the level and quality of day-today activities, the overall management of the service, a culture that does not encourage people to speak out, poor communications, and lack of involvement in personal planning for their family members. Relatives made a number of eminently sensible recommendations to address their concerns.

The events in Bungalow 3 and the attendant publicity have had a profound effect on staff. They were shocked, horrified and embarrassed about what happened, and many also felt hurt, angry and ashamed. Overall, staff were highly critical of many aspects of the service, some of which were historical and others related to more recent developments. Their criticism focused on the lack of leadership, poor management oversight and visibility, poor training opportunities in the past, and overcrowding in the bungalows with an unsuitable mix of residents. Staff felt these issues contributed to the events in Bungalow 3. Despite morale being low, a sense of hope and optimism about the future was also expressed and a number of practical and policy issues were suggested to ensure that residents are safe and protected, and realise their full potential.

The management review involved the completion of questionnaires by both senior management for the organisation and management at bungalow and unit level in the three centres. The purpose of this was to establish how many of the recommendations of the various inspections and reviews had been implemented to date. The management review also incorporated a person-focused assurance review to capture information on the organisation, management and day-to-day supports and practices at Áras Attracta.

The management review was undertaken against a backdrop of a senior management team in a state of flux over the past year, with many changes in personnel and new senior appointments. With regard to the senior management questionnaire, the overall findings indicated that the majority of the partially implemented recommendations have a completion date in 2016, and six have a longer time-scale. Most progress has been made in the areas of *meeting health and well-being needs* and *ensuring residents are safe and protected*; however most attention is required in the areas of *enabling and sustaining independence, meeting staff needs* and *leadership and direction*. At centre level, the overall findings indicated that most attention is required in the areas of *enabling and sustaining independence*, meeting *health and well-being needs*, and *ensuring the safety and protection of residents*.

The person-focused assurance findings highlighted that there was no training for residents on keeping safe and in the use of the complaints procedure. There is a 'one-size-fits-all' approach towards looking after their personal money, regardless of individual capacity. There are lost opportunities for community integration. There are considerable variations in residents' freedom to exercise choice in their daily lives; lack of privacy and personal space; and the current GP services are on a first-come-firstserved basis. With regard to how residents spend their day and learn new skills there is considerable variation in the level of activities people are involved in and how meaningful these are for each person. Residents in Áras Attracta need staff to implement personal plans through the key worker system and for staff to be well trained, knowledgeable and formally supervised. They also need a regular team of familiar staff; up-todate policies; access to an advocate when needed; and for staff to facilitate contact with family and friends.

2.2 Recommendations

The Review Group was asked to identify gaps and make recommendations for further improvements in Áras Attracta and to ensure that any learning from its work is reflected and promoted throughout the wider intellectual disability sector. For these reasons there are a number of strands to our recommendations:

- Three overarching recommendations relating directly to service delivery at Áras Attracta.
- Thirteen actions for the HSE to improve the quality of lives of people with intellectual disabilities, and to ensure national policy is fully implemented.
- An action plan for the managers of all congregated settings, as they move people to the community, in compliance with *Time to Move on from Congregated Settings* (HSE, 2011).

In arriving at its recommendations, the Review Group felt it important to propose actions that are feasible and meaningful, and that can have direct and beneficial impact on the lives of people.

Recommendations for Áras Attracta

The three overarching recommendations for Áras Attracta are:

1. A move to a rights-based social model of service delivery.

The current model of service delivery at Áras Attracta is one that promotes dependence over independence; it does not equip people to make decisions about their own lives, nor does it take account of individuals' talents or potential. It fails to respect the dignity and rights of individuals. These are all characteristics of an institutionalised congregated setting. By contrast, a rights-based social model of service delivery would:

- > Positively affirm the rights of those with a disability.
- Look at disability as a functional limitation or loss of opportunities to take part in the normal life of a community in the same way as everyone else.

The practical implications of following such a model in Áras Attracta would require:

- A much greater emphasis on person-centred practices at all levels of service.
- Actively involving each resident in developing services around his or her particular needs, circumstances and personal preferences.
- Changes in working practices and management structures.

2. The voices of residents need to be facilitated, listened to, and promoted.

Some people with an intellectual disability have considerable communications difficulties and cannot speak for themselves; others have become accustomed or resigned to a pattern of life and cannot envisage an alternative; others still have become institutionalised and are not equipped to make even simple decisions about their lives. In certain circumstances there is a requirement to infer their needs from observation, from conversation with their family members, and from the opinion of key workers and other staff in relation to their will and preference. Initiatives that might make it easier to listen to residents and to act upon their will and preferences include:

- Promotion and extension of the residents forums that have emerged in some bungalows.
- Greater attention to the expressed and inferred preferences of individual residents.
- Extension of the role of the key worker to include a remit to actively give effect to residents' preferences.
- Appointment of a community liaison officer to identify organisations, groups, sports clubs or individuals in the community with whom particular residents might share mutual interests, skills or activities.
- Ensuring that residents know their rights, have access to advocacy services and know how to make a complaint if necessary.

3. Strengthening and enhancing the leadership and management.

The patterns of support for residents in Áras Attracta and professional thinking and practices of management and staff have not kept up with national and international developments. The service has become isolated and marginalised resulting in a situation where there is no clear vision for the service and residents' futures; inadequate engagement with the community; and significant isolation from other services. In order to address these shortcomings, the leadership and management need to:

- Adopt current national policies and good practice.
- Articulate a clear vision and develop a strategic plan for Áras Attracta and communicate it widely to residents, relatives, staff and relevant others.
- Ensure that all staff have a clear understanding of their role and of the efforts required to achieve this vision.
- Ensure that residents are represented on the governance structure for the oversight of the campus,
- > Implement a leadership development programme.
- Facilitate organisational links with partners in the sector.
- > Develop a communications strategy for all key stakeholders.
- Ensure that statements of purpose reflect the characteristics of each centre.
- Improve staff morale by promoting the culture of a 'learning organisation'.

The Review Group believes that the three overarching recommendations outlined above should guide management at Áras Attracta in addressing the following deficits, which were identified in the course of our work.

Deficits in Áras Attracta				
Residents	 Absence of full life and meaningful relationships 			
	 A culture of dependency and lack of empowerment 			
	Inadequate protection			
	Insufficient opportunities to take risks			
	Insufficient access to advocates			
Relatives	Ineffective engagement in person-centred planning			
	 Untimely and insensitive communication with relatives 			
	 Lack of opportunities to be informed about changes 			
	 Poor consultation around decisions 			
	Inadequate consultation			

Staff	Absence of a strong person-centred focus	
	Low expectation of residents' potential and capacity for risk-taking	
	Inflexible staffing arrangements and frequent staff movement	
	Low staff morale	
Management	No clear vision for Áras Attracta	
	Lack of strong leadership and direction	
	 Poor communications 	
	Ineffective use of staff resources	
	 Lack of support, supervision and performance management of staff 	
	 Lack of implementation of national policy 	
	 Weak accountability and governance systems 	
Environment	 Unexplored community housing options 	
	 Poor engagement with the local community and community organisations, and underuse of transport facilities 	
	 Dearth of employment and educational opportunities 	
Policy	 Lack of awareness training for the residents and their relatives in how to use complaints and protection policies effectively 	
	Lack of staff access to and familiarity with organisational policies	
	Inadequate compliance with national disability policy	

Recommended actions for the HSE

The Review Group recommends that the following actions be taken by the HSE. These actions are in line with the HSE's *Corporate Plan 2015–2017* (HSE, 2015).

2 Make certain that structures and accountability mechanisms ensur	e that
national policy is fully implemented at local level.	
Implement a rolling programme of assessments of individual needs in all congregated settings.	
4 Ring-fence resources to support people to move out of congregate settings, ensuring that the funding follows the individuals, and tha personalised budgets are an option.	
5 Accelerate the process of supporting people to move into community living, avoiding transitional arrangements.	nity

6 Place failing services into 'Special Measures'.

- 7 In the review of *Safeguarding Vulnerable Persons at Risk of Abuse: National Policy and Procedures,* ensure that guidance is included for the development of local adult protection and welfare procedures.
- 8 Develop a mechanism for promoting good practice throughout the intellectual disability sector.
- **9** Promote voluntary advocacy services and initiatives under the aegis of the National Advocacy Service.
- **10** Ensure that HSE disability managers engage with people with intellectual disabilities and their representatives.
- **11** Develop a bespoke leadership development and management of change programme for managers of all congregated settings.
- **12** Ensure the entitlement of people with disabilities living in designated centres to access all housing supports.
- **13** Conduct a review of the foregoing actions, and provide a progress report on the recommendations and deficits in Áras Attracta, to be reported back to the Minister with responsibility for Disability Services within 12 months.

Recommended action plan for congregated settings

An action plan directed to all congregated settings is outlined below. This identifies the steps that need to be taken to support a rights-based social model of service delivery, and a move away from life in congregated settings for approximately 2,800 people with an intellectual disability who continue to live in such settings. Many of these actions are also applicable to Áras Attracta.

- 1 In line with national policy, everyone living in a congregated setting will be given the opportunity to live in the community.
- 2 Transitional monies will be provided to enable this to happen. Transitional monies are additional funding for a 12–18 month period to cover the additional costs of transition.
- **3** The move to a community setting will be individually planned, using an extensive person-centred planning (PCP) process, based on the person's will and preference, and in partnership with their family.
- 4 The supports that each person needs to live successfully in the community will be carefully assessed using the Supports Intensity Scale (SIS) or similar assessment tool. This then is the level of support that will be provided on an ongoing basis to each person.
- 5 The transition to community living will be completed over a five-year period. In year one, 15 per cent will move to a community setting; in year two, a further 20 per cent will move to community settings. Further targets will be set for the remaining three years in the light of that experience.

- **6** The HSE or voluntary body will determine appropriate alternative use for the campus as the site is vacated. Where land or property is sold, the monies realised will assist with transitional costs.
- 7 All staff currently employed will continue to work for the service provider; staff who do not wish to work in the new community settings will be offered employment in other facilities and services.

2.3 The challenge of moving to community living

Moving from a congregated setting to a community setting is a major challenge for any service provider and will require a simple, clear and explicit vision that describes what the new reality will look like. It will also require strong leadership and total commitment from all senior management to help realise this vision – there can be no 'sitting on the fence' by senior management. The challenge is to create a new kind of service that is tailored to each person's needs and priorities.

The management should engage with all stakeholders to articulate this vision for the future, and the values that will underpin the new service. The values should reflect a commitment to support a meaningful life, community participation, individual empowerment and respect for human rights.

The transition to community life will entail a fundamental change in culture, from learned dependence to personal choice and calculated risk-taking; from staff controlling people's lives to workers supporting individuals to live the life of their choosing; from people having limited options to having the same options as others living in that community, this includes healthcare needs being accessed through primary care centres and community services. Such a fundamental change will involve:

- A steep learning curve for senior management (this will involve opportunities to visit de-congregated sites, to meet with the leaders of successful transition to community settings, and to learn about the management of organisational change).
- Sharing the learning with all levels of the organisation and with people supported and their families.
- Identifying leaders at all levels in the organisation who are ready, willing and able to lead the change.
- Constant communication with all stakeholders (newsletters, websites, Facebook, Twitter, meetings, and so on).
- Formalised arrangements for regular consultation with the people supported and their families, with staff, and with funders.
- Fostering the independent voice of the people supported by the service, through self-advocacy training, speak-up groups, house forums, and so on.
- Supporting those individuals who already want to move to a community setting, through the process of transition into the community.

- Sharing the successes as they occur with all stakeholders, and learning from the challenges that arise.
- Ensuring that large-scale institutionalised living is not replaced with smallscale institutionalised living.

What will determine the success of community settings

The success of the move from the congregated setting to a community setting will be determined by a number of factors:

- The involvement of the person in all aspects of the move, including deciding where they will live, and who they will share their home with.
- The commitment of all staff and management in each setting to prepare people for the transition to community living. This preparation will focus on empowering each person to make everyday choices, to speak up for themselves, and to express preferences.
- The HSE's engagement with housing bodies (local authorities, NAMA, voluntary housing associations) and landlords and developers, to ensure a variety of housing options for people in suitable community locations.
- In identifying suitable locations, the focus will be on local facilities (closeness to shops, churches, GPs, education, sports and leisure facilities, active community groups, opportunities for part-time employment, closeness to family members, access to public transport, friendly neighbours, and so on) and personal choice.
- Engagement with education providers to explore, facilitate and promote learning opportunities.
- Focus on preparing the local community for the transition.
- As far as practical, the person will choose their own support staff.
- A transition team will have responsibility for coordinating the transition from living in the congregated setting to living in the person's chosen community location.

2.4 Áras Attracta: a bleak picture...

There was widespread institutional conditioning and control of residents in Áras Attracta resulting in limitations in their rights, choices and freedom. Institutional conditioning occurs when people living and supported in institutions react, behave and conform to established rituals and rigid routines, which are generally imposed for the ease of managing the service and convenience of management and staff. The outcomes for people living in such organisations include loss of independence, limited options and poor control over their lives.

The lack of a stimulating environment and fulfilling activities; residents spending long hours confined to their bungalows and units and without any valuable contact with the outside world; a world where the human dignity, privacy and rights of residents were not always respected or catered for; a model of service that is not organised to meet the needs, wishes and

aspirations of residents and is structured to suit staffing constraints – these are all factors that paint a bleak picture of life for residents in Áras Attracta and are the complete opposite of a person-centred and person-focused service.

Overcrowding and lack of privacy were significant issues. Some residents had their own bedrooms, while there were as many as four sharing others. Creating a homely feeling in these circumstances is difficult to achieve. Some residents had personal items (photos, furnishings, and so on) in their rooms, but others were living in dull or bleak surroundings with their beds separated by dividers and curtains. Few had a key to their own room.

There are few links with the local community and community organisations and many examples of missed opportunities in this respect – one resident was observed knitting in the day services centre while there is a thriving knitting club in the town. Mass is celebrated every week in Áras Attracta, but few residents attended the local church. There is a GAA pitch across from the main entrance to the campus yet residents who follow GAA do not attend matches.

... with some rays of hope for the future

In the course of our work we were encouraged to observe much patient, kind and sensitive support being shown by staff to residents, and it was clear that there are strong bonds of affection and dedication between staff and many residents.

In some bungalows, there were the beginnings of residents' forums that might give residents a say in what happens in their home, but we know that this voice needs greater support.

There are also some beginnings of engagement with the local community – one resident was involved in the local Tidy Towns initiative, some had joined the local library, and a small number were taking part in a programme run by the Education and Training Board. This was a recent initiative.

The HSE has prioritised Áras Attracta as one of the services which will see an accelerated implementation of the 'Transforming Lives' programme including implementation of the 'Time to Move on from Congregated Settings Report'. This is a fundamental change in the way in which services and supports for people with disabilities are currently provided which will empower them to live independent lives, provide them with greater independence in accessing the services they choose, and enhance their ability to tailor the supports required to meet their needs and plan their lives.

To support implementation of the change programme over €3m additional revenue funding has been provided to Áras Attracta in 2016 to support the development of a "Social Care Model" of service and to improve existing services and practice at the centre.

A Service Reform fund comprising of partnership between the HSE, DOH, Atlantic Philanthropies and Genio will support the implementation of the change programme, including transitional funding in the move to community living. Áras Attracta have been prioritised in this programme. In addition, for the first time government has provided a dedicated €100m capital fund for disability services over the period 2016-2021, which will support the implementation of the "Transforming Lives" programme. €20m has been provided for 2016 and Áras Attracta has been prioritised with a capital funding required to support the commencement of the first phase implementation in 2016.

Two "Social Care Model" houses opened on site in Áras Attracta in November 2015. Four residents live in each house and take part in everyday situations at home and in the community with support e.g. preparing their own meals, getting a key to their own front door, going out to the cinema, bowling or to the hairdressers etc.

All residents have had individualised assessments which indicate, that with planning and the appropriate supports, they can all transition to community living. 27 residents will move to live in the community in Phase 1 commencing in 2016.

2.5 In conclusion

The findings from our work reflect failures at all levels in the system and change to date at Áras Attracta has been driven mainly by compliance issues. The recommendations and actions outlined in this report, however, require deep transformational change.

To achieve this, the capacity for change needs to be strengthened and the pace of change accelerated so that residents who are ready to move now to a non-institutional setting in the community are supported to do so without delay. At the same time during the transition period, the Review Group is cognisant that the quality of life and the service model must be enhanced for those who remain in Áras Attracta until they too can move.

While progress has been made over the last year, the bigger structural changes outlined above have yet to be addressed.

Now is the time to face up to the deficits and failures, to listen to what residents and their families have said, to implement the findings and recommendations in this report and to concentrate all efforts on what matters most – a better future.

The HSE has developed a Roadmap that sets out the vision for the future service model at Áras Attracta and a timeline for its implementation. This will be used in a comprehensive consultation and engagement process with residents, their families, staff, unions and other stakeholders before the final action plan for Áras Attracta is agreed.

Key messages

HSE response to recommendations

The Health Service Executive (HSE) welcomes the findings of the McCoy Assurance Review and wishes to thank Dr McCoy and his team, Ms Deirdre Carroll, Dr Bob McCormack, Ms Ann Judge and all who have had input into this report. The involvement of residents and family members of Áras Attracta, staff, management, people with disabilities across the country, partners within the disability sector and external parties sees a comprehensive report that provides recommendations and actions for Áras Attracta, the HSE and the wider disability sector.

The HSE's response to the report's recommendations and actions outlines progress on service improvements that have taken place to date at Áras Attracta. It also outlines improvements in safeguarding and disability services nationwide as key initiatives were progressed by the HSE's Social Care Division and Community Healthcare Organisations (CHOs) parallel with Dr McCoy's Assurance Review. Our ongoing focus is to implement the changes required at Áras Attracta to ensure the safety and wellbeing of all residents and to ensure that they, and their families, are consulted with, and involved in, the transition to a community based model of living and support. By the end of 2015, as referenced in the report, more than 60% of all the recommendations in the reviews conducted at the Centre since 2014 had been implemented, and further progress is being made during 2016. Significant further improvements are under way in Áras Attracta in line with its agreed vision, which is:

Vision for Áras Attracta

"To move from an institutional model of care to a community based, person centred model, enabling and supporting meaningful lives as chosen by service users, within the resources available and in line with national policies"

In working towards this vision, while at the same time ensuring ongoing service improvements, the approach to reforming services has been adopted as follows:

• Transition to community living

Accelerate the transition to a person centred, community based model of support in line with the policy *Time to Move on from Congregated Settings* (HSE, 2011) and the wider disability reform programme, *Transforming Lives* – which is the programme to implement recommendations of the *Value for Money and Policy Review (VFM) of Disability Services* (Department of Health, 2012).

• Improve current services

Improve current services, safeguarding, and compliance with HIQA residential standards for disability services (2013) through the implementation of the new National Policy on Safeguarding and the 'Six Step' change programme for Social Care services.

• Develop a Roadmap for services at Áras Attracta

In line with this approach to service improvement and reform and the initial consultation with residents, their families and staff at Áras Attracta, the HSE has developed a *Roadmap* that sets out the vision for the future service model at Áras Attracta and a timeline for its implementation. This is informed by the McCoy Assurance Review.

This response from the HSE encompasses much of what is outlined in the *Roadmap* which will be used in a comprehensive consultation and engagement process with residents, their families, staff, unions and other stakeholders before the final development plan for Áras Attracta is agreed. The development plan, once implemented, will enable residents to transition to community living and live meaningful lives of their choice with the appropriate supports.

The individual needs assessments of all residents in Áras Attracta which were completed by December 2015, will inform individual care plans for residents. Implementation will be on a phased basis with 27 residents to transition in Phase I, commencing in 2016. Phase II, commencing in 2017, will see a further 26 residents transition. In accordance with their individual needs assessments, these residents will require significant additional support and time to progress to community living. Phase III will involve a comprehensive programme of communication and engagement with 37 residents and their families about choices and options for their future. Phase III residents have significant complex needs, ageing or medical conditions and will require additional transitional planning and time to ensure that the most appropriate supports and service are provided for them in accordance with their individual needs assessments. Planning has already commenced for this third phase, and will be implemented in consultation with service users, their families and advocates to ensure the best outcome for each individual.

Enabling the change programme at Áras Attracta

Governance:

A comprehensive new governance structure, with strengthened leadership and management capabilities has been put in place to oversee the effective implementation of the change programme. The Implementation Team is comprised of:

- The *Director of Services* and the team responsible for day-to-day management of the service,
- A dedicated *Project Manager*, with significant experience in quality improvement and enabling transition of people from congregated to community settings in Ireland and internationally,
- HR, Risk Management, HSE Estates and Communications capacity are enabling the change programme.

Work streams have been established to deliver key elements of the change. Residents, family members, staff from all grades and professions and representatives from voluntary partners within local disability services are included in the work streams.

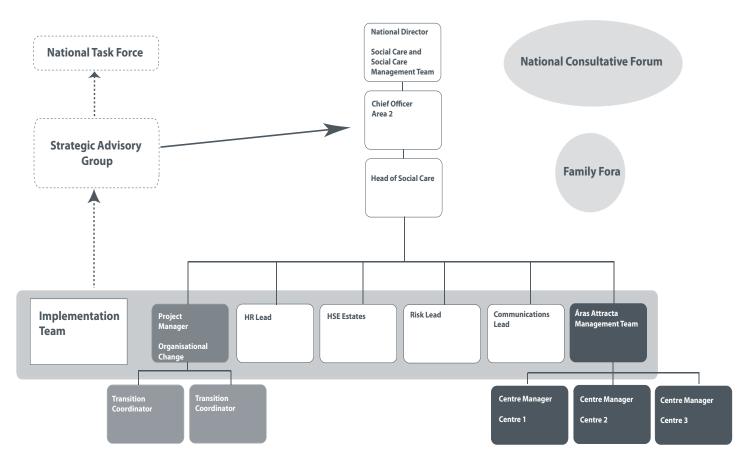


Figure 1: New governance structure at Áras Attracta

The dedicated change management resource consists of a Project Manager with significant experience in quality improvement and enabling transition of people from congregated to community settings in both Ireland and internationally. The Project Manager is supported in her role by two transition coordinators who have completed significant training in the area of Social Role Valorisation. The Project Manager is directly responsible for engaging with all stakeholders, including estates, housing associations, other service providers and other state bodies in order to progress transition to community living.

Strategic Advisory Group:

The McCoy Review Group recommended, and the HSE accepted, the requirement for a Strategic Advisory Group to support the implementation of the change programme. This group will consist of a small senior group of experts to advise, support and challenge the Chief Officer and the Implementation Team on the change programme as it progresses. The new governance structure outlines the new leadership and management team which will oversee implementation of the change programme reporting to a new head of Social Care in the Community Healthcare Organisation. The strategic advisory group will report to the Chief Officer who has overall responsibility for responsibility for this comprehensive change programme.

We are confident that the changes being made in Áras Attracta to improve services and safeguarding will ensure an improved quality of life for all concerned through the creation of a community model of living and supporting residents to choose where they live, how they live and who they live with. Significantly, and for the first time, dedicated capital resources through the Capital Programme, and transitional funding by the Service Reform Fund, have been made available in 2016 to support implementation.

Improvements in leadership and management:

Initiated in July 2015, and completed by November 2015, the first major recommendation emerging from the McCoy Review Group, that the HSE adopted, was the change of governance structures within Áras Attracta.

Prior to July 2015, Áras Attracta was regarded as a single centre and a reorganisation into three designated centres was recommended along with a change in the model of care from a traditional medical model to a rights-based social model of care and support. In line with this, a full-time on-site Director of Services and three centre manager posts were appointed following an external recruitment process to improve leadership and management of day-to-day services. Under the leadership of the new Director, three distinct centres now operate within the campus, headed by a new person in charge responsible in each centre, with one centre each providing:

- Services to residents with intellectual disability with complex health needs and high physical dependency
- Services to residents with intellectual disability and behaviours that challenge
- Support to residents with an intellectual disability and medium levels of dependency

This governance structure brings management closer to the point of service delivery, providing opportunities to concentrate on improving standards of care, and delivering better outcomes for the residents.

Key improvements and progress to date can be summarised as follows:

Transition to Community Living in Áras Attracta

Building a Community Model of Support

- Individual needs assessments have been completed for all residents to identify their future support requirements to live a successful life in the community.
- Enhanced independence and community integration for those living at Áras Attracta e.g. supported employment for residents, residents joining local GAA club, participating in cookery classes in the local community, transferring to community based GP services etc.
- Two "Social Care Model" houses opened on-site in November 2015 with four residents in each taking part in an everyday normal life situation and integrated into the local community.
- Detailed implementation planning is under way to support residents to transition to community living on a phased basis.
- €20m national capital investment by Government in 2016, with Áras Attracta prioritised for €2m capital funding to purchase seven properties which will support 27 residents to commence transition to community living in 2016 in line with their preferences.
- €3.2m additional revenue funding has been provided in 2016 to support the new model of service.

• The Service Reform Fund 2016 (partnership between HSE Social Care and Mental Health Divisions, Genio, Atlantic Philanthropies and Department of Health) will provide "transitional funding" to support Áras Attracta to implement the community model of service.

Improving Services Today in Áras Attracta Enhancements in safeguarding at Áras Attracta

- All staff have undergone safeguarding training.
- Resident specific safeguarding education programme has been developed.
- A permanent senior social worker has been appointed.
- Safeguarding Governance Group has been established with Dr Andrew McDonnell (Studio 3) as Chair.
- Studio 3 approach to support people in challenging situations has been introduced.
- An enhanced incident management structure is in place with daily monitoring of incidents, regular review and analysis and monthly review by an oversight committee which has external representation.
- A robust complaints management structure is now in place.
- National support is provided by the HSE's Quality Improvement Enablement Programme.

Training and new approaches at Áras Attracta

- 34% of staff have completed key worker training.
- Studio 3 have provided staff training to support people in challenging situations, and in providing advice and support to frontline staff. Their approach uses a low key non-confrontational approach to manage behaviours that challenge.
- The three designated centres in Áras Attracta have core teams of staff and key workers working consistently with residents in place, resulting in enhanced relationships between staff and residents.
- Three staff have commenced Social Role Valorisation training, provided by Genio.
- Social care model information sessions are being provided by the Centre for Nurses and Midwifery Education.
- Following training of some staff, measurement of residents' quality of life has commenced using the Person Outcomes Measures Tool.
- Formal support and supervision for all staff will commence shortly.

Promotion of residents' voices and improved communication with families

- Time and attention is now given to obtaining the expressed and inferred preferences of residents by including them in determining their futures through 'Discovery' work, advocacy and ongoing consultation with residents and their families.
- The Áras Attracta communication policy has been reviewed and a user friendly template has been devised for residents' meetings, which are held monthly.
- A number of residents are involved in the "Voices and Choices" group, which meets weekly.
- Weekly house meetings take place in the new social care model houses opened on-site.

- A user friendly pictorial guide has been developed to support residents in making a complaint.
- An information session on self advocacy has been provided to residents who are supported to access advocacy services. A number of residents are now engaging with the Independent Advocacy Service/National Advocacy Service.
- A Family Forum was developed in collaboration with Inclusion Ireland (September 2015).
- Nominations have been sought from residents and family members to participate in the project team work streams, tasked with delivering the change programme at Áras Attracta.

Governance and performance management at Áras Attracta

- Áras Attracta was reorganised into three centres based on residents' needs (completed November 2015).
- Following an external recruitment process, a full-time on-site Director of Services has been appointed along with dedicated managers to each of the three designated centres to improve leadership and management of day-to-day services.
- The Director of Services and three centre managers undergo regular performance management.
- Enhanced meeting schedules all meetings from the "home" meetings to the management steering group meetings are now scheduled.
- Regular unscheduled and scheduled visits to all areas of the campus take place by the Chief Officer for CHO 2, the Director of Services and the three Centre Managers.
- Enhanced staff accountability is now in place including implementation of the HSE's Grievance and Disciplinary Procedure when required.

Investment in staffing at Áras Attracta

An additional investment of €3 million in staffing has resulted in the recruitment of the following staff:

•	23 Social Care Workers	•	5 Psychology Project Workers (Studio 3)
•	3 Social Care Leaders	•	1 Senior Dietician
•	33 additional Healthcare Assistants	•	1 Senior Speech and Language Therapist
•	1 full-time Director of Services	•	1 Occupational Therapist
•	3 new Centre Managers	•	1 Senior Physiotherapist
•	1 Lead Social Worker	•	1:1 or 2:1 staffing supports in place where required

Improved compliance with HIQA residential standards

A HSE and HIQA information sharing group, which meets bimonthly, was established.

• Joint approach agreed in October '15 between HIQA and the HSE, implemented through a combination of self assessments and ongoing HIQA inspections.

- Positive verbal feedback received from most recent HIQA unannounced inspection visits to the three centres on the 30th and 31st of March – report awaited.
- Improvements to date acknowledged by HIQA who are particularly impressed with the work done on-site in the social care houses.
- Enabled by the additional investment in staffing, six additional accommodation units have opened on-site since January 2015.

HSE Response to recommendations – wider disability sector reform

The Six Step Change Programme

- In tandem with the work of the McCoy Review Group, a six step system wide programme of measures to enhance service quality and improve safeguarding practice in disability services was established in December 2014. Led by the National Task Force, the purpose of the six steps is to give oversight and direction to local plans and local action, and to ensure quality and safety of all services through empowering and safeguarding vulnerable people.
- To date, the Six Step Programme has had a significant focus on improving the safety, welfare and quality of life for persons with a disability. Key components of the Six Step Programme are as follows:



Figure 2: Six Step Programme for disability services reform

Key measures

The Key measures being implemented are outlined below.

The National Implementation Task Force

The National Implementation Task Force chaired by the National Director, was established to drive implementation of the overall programme and the development of long-term sustainable and evidence-based safeguarding

practices and training programmes specific to residential settings. The taskforce includes all Chief Officers of Community Healthcare Organisations (CHOs), representatives of voluntary service providers and service users, Inclusion Ireland, National Disability Authority (NDA) and Tusla.

A key challenge for the Task Force is to identify how service providers, service users, families and advocates can build capacity together to ensure organisations can respond to each individual's wants and needs to live the life of their choosing. The challenge for services is to support people to choose where they live, who they live with, and to ensure they have choices around what they do every day, with tailored supports for each person.

National safeguarding policy implementation

In December 2014 the HSE published its policy on Safeguarding Vulnerable Persons at risk of abuse. This policy seeks to provide a consistent approach to protecting vulnerable people from abuse and neglect, to ensure all services have a no tolerance approach to any form of abuse, and to promote a culture that supports this ethos.

The new policy has been widely communicated to staff and volunteers and its implementation overseen by the new Chief Officers of the Community Healthcare Organisations (CHOs). Safeguarding teams have been established in each of the nine CHOs led by a Principal Social Worker and 33 additional staff have been appointed to:

- Receive reports of concerns and complaints regarding the abuse of vulnerable persons from Dedicated Officers in all HSE and HSE funded services.
- Support services and professionals to assess and investigate the concern(s) / complaint(s) and develop intervention approaches and protection plans.
- Directly assess particularly complex complaints and coordinate service responses.
- Support, through training and information, the development of a culture which promotes the welfare of vulnerable persons, and the development of practices which respond appropriately to concerns or allegations of abuse of vulnerable persons.
- Maintain appropriate records.

A **National Inter-Sectoral Safeguarding Committee** has been established, independently chaired by Ms Patricia Rickard Clarke, former Law Reform Commissioner. The committee has representation from a number of organisations, both within and external to the HSE, and will give strategic direction on developments to promote the protection of vulnerable adults. Specifically, the group will:

- Provide strategic direction to the HSE in relation to safeguarding.
- Lead on promoting a societal and organisational culture that promotes the welfare of vulnerable adults.
- Provide oversight and guidance on policies and procedures required to ensure concerns are addressed appropriately.
- Propose the commissioning of research, public awareness campaigns and training aimed at promoting the welfare of vulnerable adults.

A priority for the Inter-Sectoral Committee is to examine and propose a public awareness campaign for vulnerable adults.

The Quality Improvement Enablement Programme

A joint initiative was launched between the HSE's Social Care and Quality Improvement Divisions in 2015 to support care improvements in residential services for adults with disabilities. The Quality Improvement team visit the service units to establish the issues that need to be addressed. A plan is then designed, with the staff, to implement the changes required. Since August 2015, the Quality Improvement team has visited 148 houses/units provided by the statutory sector encompassing 1,054 HIQA registered beds throughout the country. They have provided intensive support to strengthen leadership and governance structures, improve person to person care planning documentation and, most importantly, to progress HIQA action plans, following inspections, and monitor where further supports are required in areas of non-compliance.

The National Volunteer Advocacy Programme

- As part of the Six Step Programme, working with families and service users, a national Volunteer Advocacy Programme in adult disability residential settings was initiated in 2014. Following a mapping exercise of existing advocacy structures, supports, frameworks, and pathways for people with disabilities, SAGE (Support & Advocacy Service for Older People) has been requested to develop and pilot a volunteer advocacy service for people with disabilities in the South East. This will inform the development of proposals at a national level for future implementation. €150,000 has been provided for this initiative.
- To support the development of Family Fora in residential centres, the HSE asked Inclusion Ireland to develop and support the emergence of an independent voice for persons with a disability and family members who access disability services in a number of residential settings. Inclusion Ireland, funded by the HSE, are developing Family Fora in a number of these centres. The design, terms of reference, and approach is being determined through local consultation and tailormade to local need.

Assurance (McCoy) Review

• A key component of the Six Step Programme is the McCoy Assurance Review, the output of which is contained in this report and the learning from which will be implemented as part of the Six Step Change Programme.

Appointment of Confidential Recipient

 In 2015, the Director General of the HSE appointed Leigh Gath, a well-known disability advocate, as a Confidential Recipient, to whom anyone can make a complaint or raise concerns about the care and treatment of any vulnerable person receiving residential care in HSE or HSE funded residential centres. Ms Gath has completed her first year in post in March 2016 and published her first annual report.

Transition to community living – national level

The focus at national level is to accelerate the transition to a person centred, community based model of support in line with the policy set out in *Time to Move on from Congregated Settings* (HSE, 2011) and the wider disability reform programme, *Transforming Lives* – which is the programme to implement recommendations of the *Value for Money and Policy Review (VFM) of Disability Services* (Department of Health, 2012).

- Through the implementation of *Transforming Lives* and the Six Step Programme, the HSE will progress the implementation of the McCoy review. The HSE's aim is that residential services are provided in family sized units in local communities. In this context, the HSE is working with service providers in the disability sector to move from institutional models of care to community living. The aim is to enable people with disabilities to live meaningful lives of their choosing in their local communities. This change is being delivered in consultation with people with disabilities, their families and local communities working with partners in the voluntary sector.
- Priority will be given in 2016, to targeting the transition of people from large institutional settings to a community based model of person-centred supports. This initiative will focus on statutory and voluntary sector residential centres who have significant challenges in achieving compliance with HIQA's National Standards for Residential Services for Children and Adults with Disabilities.
- Capital funding of €100m for disability services is being provided by government over the period 2016–2021. This funding, together with the additional 'ELS' funding provided in the 2016 budget for compliance with HIQA standards, will enable supports to be reconfigured and accommodation secured, to commence the transition to community living for at least an additional 160 service users in 2016.

Service reform fund

A service reform fund established between Atlantic Philanthropies, the Department of Health, HSE Social Care and Mental Health services and the Genio Trust will support the phased transition to a person-centred model of services. This will provide funding for a number of innovative projects in line with the policy set out in *A Time to Move on from Congregated Settings* policy and the wider *Transforming Lives* agenda that will facilitate individuals to transition into the community.