Policy Advice based on the review of the implementation of regulations and inspections in residential services for adult and children



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Contents

[1. Overview 6](#_Toc489622417)

[1.1 Context 6](#_Toc489622418)

[1.2 Regulatory system should promote reform agenda set out in national policy 7](#_Toc489622419)

[2. Summary of advice 8](#_Toc489622420)

[3. Advice in relation to the regulatory process 9](#_Toc489622421)

[3.1 Legislation 9](#_Toc489622422)

[3.2 Definitions 9](#_Toc489622423)

[Advice 11](#_Toc489622424)

[3.3 Registration of designated centres 11](#_Toc489622425)

[Advice 12](#_Toc489622426)

[3.4 Arrangements for care of residents if registration is cancelled 12](#_Toc489622427)

[Advice 13](#_Toc489622428)

[Advice 14](#_Toc489622429)

[4. Regulations 15](#_Toc489622430)

[4.1 General comments 15](#_Toc489622431)

[Advice 16](#_Toc489622432)

[4.2 Commentary on Specific Regulations 17](#_Toc489622433)

[4.3 Registration of Designated Centres for Persons (Children and Adults) with Disabilities Regulations 2013, S.I. No. 366 of 2013 17](#_Toc489622434)

[4.4 Care and Support of Residents in Designated Centres for Persons (Children and Adults) with Disabilities Regulations 2013, S.I. No. 376 of 2013 17](#_Toc489622435)

[5. Residents’ rights 19](#_Toc489622436)

[5.1 UN Convention on the Rights of Persons with Disabilities 19](#_Toc489622437)

[5.2 Residents’ rights 20](#_Toc489622438)

[5.3 Engagement with the HIQA process 21](#_Toc489622439)

[The recommendations in relation to information and education are divided into things people recommend happens: Before an inspection visit 21](#_Toc489622440)

[During an Inspection visit 21](#_Toc489622441)

[After an inspection visit 21](#_Toc489622442)

[Meeting the inspector 21](#_Toc489622443)

[Consent 22](#_Toc489622444)

[The inspection team 22](#_Toc489622445)

[Advice 23](#_Toc489622446)

[6. HIQA 25](#_Toc489622447)

[6.1 The inspection process 25](#_Toc489622448)

[Advice 25](#_Toc489622449)

[6.2 Verification processes used by HIQA 25](#_Toc489622450)

[Advice 25](#_Toc489622451)

[6.3 Ongoing training for HIQA inspectors 26](#_Toc489622452)

[Advice 26](#_Toc489622453)

[6.4 Developing action plans 26](#_Toc489622454)

[Advice 28](#_Toc489622455)

[6.5 Action plans and staffing issues 29](#_Toc489622456)

[Advice 30](#_Toc489622457)

[Nursing staff 30](#_Toc489622458)

[Advice 30](#_Toc489622459)

[7. Continuous quality improvement 31](#_Toc489622460)

[7.1 Service provider initiatives 31](#_Toc489622461)

[Advice 32](#_Toc489622462)

[7.2 HIQA’s role 32](#_Toc489622463)

[Advice 32](#_Toc489622464)

[7.3 Thematic inspections 33](#_Toc489622465)

[Advice 33](#_Toc489622466)

[8. Leadership, culture and practice 34](#_Toc489622467)

[8.1Good practice 34](#_Toc489622468)

[8.2 Leadership, culture and practice 34](#_Toc489622469)

[Advice 35](#_Toc489622470)

[Appendix 1 40](#_Toc489622471)

[Advice on specific regulations 40](#_Toc489622472)

[A.1 Commentary on Specific Regulations 40](#_Toc489622473)

[A.2 Registration of Designated Centres for Persons (Children and Adults) with Disabilities Regulations 2013, S.I. No. 366 of 2013 40](#_Toc489622474)

[Advice 41](#_Toc489622475)

[Advice 41](#_Toc489622476)

[Advice 42](#_Toc489622477)

[A.3.3 Care and Support of Residents in Designated Centres for Persons (Children and Adults) with Disabilities Regulations 2013, S.I. No. 376 of 2013 43](#_Toc489622478)

[A.3.1 Care and Support Regulations, Regulation 4, Written Policies and Procedures 43](#_Toc489622479)

[Advice 43](#_Toc489622480)

[Advice 44](#_Toc489622481)

[A.3.3 Care and Support Regulations, Regulation 8, Protection 45](#_Toc489622482)

[Advice 45](#_Toc489622483)

[Advice 45](#_Toc489622484)

[Advice 45](#_Toc489622485)

[A.3.6 Care and Support Regulations, Regulation 12, Personal Possessions 46](#_Toc489622486)

[Advice 46](#_Toc489622487)

[A.3.8 Care and Support Regulations, Regulation 16, Training and Staff development 47](#_Toc489622488)

[Advice 47](#_Toc489622489)

[Advice 47](#_Toc489622490)

[Advice 48](#_Toc489622491)

[Advice 49](#_Toc489622492)

[Advice 51](#_Toc489622493)

[Advice 51](#_Toc489622494)

[A.3.14 Care and Support Regulations, Schedule 6, Matters to be provided in premises of designated centres. 51](#_Toc489622495)

[A.3.15 Care and Support Regulations, Schedule 6, no reference to single bedrooms 52](#_Toc489622496)

# 1. Overview

## 1.1 Context

The National Disability Authority was asked by Kathleen Lynch T.D., Minister of State for Primary Care, Mental Health and Disability, to conduct an independent review of the process for the implementation of regulations and standards in residential services for adults and children with disabilities.

The National Disability Authority completed this review over the course of a year and provided a draft report of its findings to the Minister in October 2015 and a final report in December 2015

The National Disability Authority’s review was primarily focused on Year 1 of inspections which were commenced by HIQA in November 2013. Typically, HIQA inspections take place over a three year cycle. Given the short timeframe within this regulatory process, the National Disability Authority acknowledges that

* it would be expected that changes would take place over the three year cycle
* there is a certain “bedding down” required with regards to the readiness of the sector for a regulatory regime and as HIQA’s own knowledge and understanding of this sector evolved
* In assisting service providers to get ready for inspection, HIQA carried out a large number of monitoring inspections before a full registration inspection was carried out. However further rounds of inspection may take a more thematic approach which could focus in on the issues central to the quality of people’s lives
* residential services for people with disabilities were not immune to the economic and fiscal challenges facing Ireland as a whole, when HIQA inspections commenced in 2013

The National Disability Authority hopes that the advice set out in this paper provides a positive contribution to the changes and transformation of disability residential services that are underway. While this advice paper is focused on the process concerning the implementation and inspection of standards and regulations for residential services, the National Disability Authority advises that it is critical that the necessary systems and supports to ensure that the **Transforming Lives** agenda is progressed so that people with disabilities can have 'ordinary lives in ordinary places'. In principle, the National Disability Authority would recommend any investment in service improvement, arising from the HIQA findings, needs to be consistent with the new model agreed, rather than, shoring up the old, although the National Disability Authority recognises that there are urgent needs that have to be addressed in situ pending the move to a new model of service. Please note that this advice paper therefore needs to be considered within the larger policy context of **Transforming Lives** Report and the ratification of the **UN Convention on the Rights of Persons with Disabilities**.

This advice paper sets out a number of recommendations in key areas, with a view to:

* Guiding improvements in the HIQA process of inspections of residential services for adults and children with disabilities
* Reviewing current legislation and regulations to have a more robust and effective regulatory system aligned with national policy and standards that maximises the opportunities for people with disabilities to “live ordinary lives in ordinary places” of their choosing
* Bringing about the changes in leadership, culture and practice that transforms residential service delivery and is essential to upholding and facilitating individuals with disabilities to exercise their human rights
* Informing a better coordinated and coherent approach to providing quality residential services for children and adults with disabilities

## 1.2 Regulatory system should promote reform agenda set out in national policy

As a guiding principle, the National Disability Authority’s advice is that the system of regulation, standards and inspection, and the legislative framework around that, should promote the national policy of supporting people with disabilities to live ‘ordinary lives in ordinary places’. In principle, this means any investment in service improvement, arising from HIQA findings, should be consistent with the new model of residential service as set out in **Time to Move on from Congregated Settings,** rather than, shoring up the old model. The National Disability Authority acknowledges that there are urgent needs that have to be addressed in situ pending the move to the new model of service.

The National Disability Authority’s advice recommends a number of actions that will also enhance the change programme underway with regards to the implementation of Government policy. This is detailed in the Report of the Working Group in June 2011 –**Time to Move on from Congregated Settings** – in moving people from congregated settings to the community, as well as, the work commenced under **Transforming Lives – Value for Money and Policy Review of Disability Services.**

# 2. Summary of advice

The following is a summary of more detailed advice contained in this paper. It provides a brief overview of the key areas of advice covered in this paper, while a table summarising the areas and who would have leading responsibility for actions arising can be found on page 26 of this paper:

* Examination of Primary Legislation including regard to definitions, registration requirements, impact of closures and the implications of Assisted Decision Making (Capacity) Act 2015
* Review of Regulations i.e. a comprehensive review of the current regulations. Issues concerning specific regulations are also highlighted for attention
* Ensure residents’ rights are upheld including giving of consent, access to advocacy, communications and awareness
* Reviewing the HIQA inspection process with regard to disability competence, training, verification processes, audits and shared learning
* Promoting good practice by identifying it, having mechanisms for structured shared learning, training and education for Persons in Charge, an on-line portal for learning, annual reports and thematic inspections
* Leadership, culture and good practice through effective communications, meaningful engagement with residents, translation of learning into practice, and focus on quality of life
* Consideration of longer term developments such as a commissioning framework for supports

# 3. Advice in relation to the regulatory process

## 3.1 Legislation

The **Health Act 2007** provides the statutory basis for the regulation, registration and inspection of residential services provided to people with disabilities and to children under the **Child Care Acts**, and to other dependent persons**.** This encompasses residential services (including respite services) where the care is provided by the Health Service Executive (HSE), as well as, by private or voluntary providers having arrangements governed by sections 38 or 39 of the **Health Act 2004** or section 10 of the **Child Care Act 1991**. Section 2(1) of the **Health Act 2007** defines these residential services as "designated centres".

A number of points arose regarding the **Health Act 2007** in the course of the National Disability Authority’s review. The National Disability Authority would highlight the following:

* Definition of designated centre
* No definition of what a “residential service” means
* Reinforcement of “institutional” models of accommodation
* Conflicting roles for HSE as service provider and the body responsible for care of residents when registration is cancelled in a HSE service

In setting out its advice in relation to these issues, the National Disability Authority acknowledges that some terms such as ‘designated centre’ apply across a number of different sectors. The National Disability Authority recognises that it is a complex matter to consider how any change in definitions or terminology to better fit the service model for disability services might be achieved, without potential legal implications for other sectors.

## 3.2 Definitions

“A ‘designated centre’ means an institution – at which residential services are provided...” (page10, Part 1, Health Act 2007) and in S.69- (1) “in this section an ‘institution’ means any – (c) home or part of one”

While HIQA have published guidelines on Designated Centres, the National Disability Authority found that there is still a lack of clarity among service providers as to what constitutes a “designated centre”.

This lack of clarity was further compounded in issues like:

* the determination of what HIQA describes in its guidance document[[1]](#footnote-1)as “real and substantial” control over the residential service, which goes beyond who owns the premises to issues like who decides which residents will live together
* that designated centres, which had been regarded as ‘health facilities’, had not been considered eligible for the Department of the Environment’s capital grant for buying a property under guidelines for the **Capital Assistance Scheme**[[2]](#footnote-2)

The **Health Act 2007** states, that “an institution means a home, centre or institution or part of a home, centre or institution”. The National Disability Authority notes that this may include a broad range of settings including large, single site congregated settings, group homes, community settings and single occupancy residential units.

In addition, the National Disability Authority also recognises that disability service providers provide residential support services to people living in an increasingly diverse range of residential settings. These settings include housing provided through local authorities, housing associations, rented from private landlords, or the original family home. This is in line with the principle set out in the **Housing Strategy for People with Disabilities** whereby housing authorities are to be responsible for provision of housing, and HSE-funded services are responsible for the provision of personal support services. It is important to clarify in the legislation, what settings and what residential support services are covered by the regulatory and inspection system. In any revision of the legislation, there needs to be scope to draw a distinction between the premises and the residential supports provided to the occupants.

The National Disability Authority believes it would be important to have a clear definition of what constitutes a “residential service”. This would alleviate some of the issues, relating to certain living arrangements, currently being classified as “designated centres”.

In addition, the National Disability Authority would be concerned that certain legal terminology, such as “institution” may re-enforce “institutionalisation” and does not necessarily reflect the spirit of the policy of people living ordinary lives in ordinary places.

This sense of “institutionalisation” could, also, be inferred from other sections of the **Health Act 2007**, such as, S. 56 – (1) where it states:

“The registered provider carrying on the business of a designated centre shall ensure the certificate of registration issued for the designated centre is affixed in a conspicuous place at the centre”

### Advice

1. The Minister to consider amending the **Health Act 2007** to bring clarity in defining “designated centres” and “residential services”. In examining the options for changes to the definition, the Minister for Health might consider:

* having one set of Regulations to apply, where, the residential premises is provided by or under the control of the residential service provider; and
* having another set of Regulations to cover situations, where, the residential premises is provided by the individual themselves or by an unconnected body, such as, a local authority.

Changes to the definition should also recognise the implications of the **Assisted Decision-Making (Capacity) Act 2015** regarding the capacity of individuals to execute tenancy agreements in their own right.

1. While it is critical to have a robust legal basis, consideration should also be given to the use of language, that better reflects the policy of living within the community and in a domestic setting.

## 3.3 Registration of designated centres

The **Health Act 2007** states:

S. 46 (1)”A person shall not carry on the business of a designated centre unless the centre is registered under this Act and the person is a registered provider”

Under this legislation all proposed new centres must apply for, and be granted, registration prior to providing residential services, The National Disability Authority notes that it is the legal responsibility of the service provider to declare a centre as a designated centre if it falls within the provisions of the **Health Act 2007**. So in the context of decongregation, it is the service provider who is responsible for identifying whether or not the new living arrangements for a resident moving out of a congregated setting is or is not a designated centre under the Act. The National Disability Authority also notes that some people may move from a designated centre to a living arrangement, which is not a designated centre.

The National Disability Authority’s research identified a number of issues relating to the implementation of Government policy regarding congregated settings and where residents are moving to new living arrangements, which are constituted as designated centres. These issues include:

* The need for designated centres to be registered well in advance of an individual moving in, resulting in potentially wasted resources and properties being left vacant while awaiting registration
* The timeframes involved in having a centre registered and how this does not necessarily align with the transition planning for an individual to move out of a congregated setting
* The need to register temporary accommodation which a person might use while their home is being renovated as a registered centre
* Lack of clarification in relation to the deregistration of properties where a property may have been registered inappropriately

### Advice

1. That the Minister considers amending this section of the **Health Act 2007** to address the issues outlined above by:

* including specific provisions to allow for speedy registering of temporary accommodation
* allowing temporary operation of a centre to facilitate the uptake of available accommodation for people moving out of congregated settings within a reasonable specified timeframe
* examining whether the full suite of Regulations should apply in the case of such temporary or fast-track registrations

## 3.4 Arrangements for care of residents if registration is cancelled

Section 64 of the **Health Act 2007** refers to arrangements for the care of residents on cancellation of registration. It states that if the chief inspector of HIQA cancels a registration under the Act and the cancellation takes effect, the HSE shall as soon as practicable after notification of cancellation make alternative arrangements for the residents of the designated centre. However, a conflict of interest arises where the designated centre is staffed and managed by the HSE in the first instance. Currently under the Act if the registration is cancelled by HIQA, the HSE are required to continue to run the centre.

This is particularly challenging where the HSE personnel are found to be unfit. It then requires HSE to find different competent staff. This can also be highly disruptive to residents, especially where continuity may be an important aspect of support. However, the safety and well-being of residents is paramount.

### Advice

1. In the short term, it is critical that in HSE-run residential services, especially larger institutions of 10+ residents, that the findings of the **Quality Improvement Enablement Programme** are acted upon. This is especially urgent regarding the up-skilling of staff. Nationally, the HSE should put in place an agreed monitoring process to ensure that training and up-skilling is reflected and actioned at a local level in practice.

In the longer term, the National Disability Authority is of the view that the responsibility for day to day running of designated centres should move from the HSE, whether through a separate public agency or otherwise, to a different provision system, and implement a ‘purchaser/provider’ split. The National Disability Authority has run expert seminars, engaged in consultation, and prepared a Briefing Paper to the Department of Health and the HSE on a **Commissioning Framework for Disability Services**. It is the National Disability Authority’s view that a Commissioning Process provides an important opportunity to reconfigure existing residential services and for funding residential services based on national policy and aligned with an individual’s assessed needs. Such a process would enable the HSE move from a direct service provider role and remove some of the anomalies that currently exist in the legislation.

The National Disability Authority is aware that the word “commissioning” is currently being used within disability services in situations where it effectively refers to a tendering process or a service level agreement between the HSE and a service provider. There are also elements of a commissioning framework in place in services. However, there is not an agreed Commissioning Framework for disability services. The development of such a framework would include consideration of, such things as

* The legal and industrial relations implications of moving from the current model of funding to a commissioning model
* How service providers could be best supported in making the move
* The needs of residents, especially people with intellectual disability, and the need for continuity
* Engagement and communicating with residents and families etc

The National Disability Authority notes that the Minister for Public Expenditure and Reform has begun a public consultation process in relation to commissioning of Human, Social and Community services and has published a paper in this regards.

### Advice

1. That the responsibility for day to day running of designated centres should over time move from the HSE to either a separate public service or to other service providers. To facilitate this transition a Commissioning Process should be established. A move to a Commissioning Approach would facilitate the purchaser/provider split. The Commissioning Process should ensure that the residential services secured address the identified needs of adults and children in residential services.
2. The Commissioning Process should include the following series of separate stages:

* Assessing the needs of people currently in residential services
* Setting service priorities and goals
* Securing services from providers to meet those needs
* Monitoring and evaluating outcomes for people in residential services

# 4. Regulations

## 4.1 General comments

A number of issues were raised during the National Disability Authority’s review in relation to the regulations for disability residential services:

* A significant number of interviewees noted a **discrepancy between the standards and the regulations.** Overall, participants seemed very satisfied with the standards. However, many stakeholders and service providers were of the view that the standards were very person-centred while the regulations were not
* Some stakeholders reported that they had an issue with the **lack of consultation** and the fast pace at which the regulations were developed
* Some people commented that certain regulations include **requirements that reflect an institutional model of living rather than an ordinary home**. Many people commented in the interviews that this was because the regulations were based on the regulations for older person’s residential settings or a ‘nursing home model’
* The importance placed by HIQA on risk assessments and risk management was highlighted. Some stakeholders emphasised the need for **positive risk taking** to ensure that people with disabilities are encouraged to lead ordinary lives in ordinary places and to engage fully with their local communities. The National Disability Authority notes that HIQA have published guidance on supporting people’s autonomy[[3]](#footnote-3)
* It was also commented that the regulations are covering a wide range of residential settings which range from 2-3 people living together to larger settings with 50 or more people. **The regulations were criticised for having a ‘one size fits all’** **approach**, resulting in inappropriate requirements for some homes, particularly for homes in the community with small numbers of people living together and which are in line with national policy and good practice
* The level of responsibility and legal implications of the person in charge role was raised. Persons in charge highlighted the fact that, although they are ultimately responsible for many aspects of the regulations and standards, they are often not in a position to make the necessary changes to ensure compliance, for example, to agree funding for building adaptations, to change staff rosters or bring in new staff, to develop organisational policies

### Advice

1. The Department of Health should conduct a comprehensive review of the regulations to maximise the quality of life for people in residential services while ensuring their safety. The review should:

* be cognisant of the need for consistency between the regulations and the national standards, while acknowledging that Regulations must be legally precise. It is also noted that Regulations and Standards have different functions
* provide clarity on the purpose of regulations and the differences between regulations and standards
* involve a consultative process with all stakeholders including residents, family / significant others, advocates, service providers, HSE and HIQA
* aim for consistency between regulations and national policy on ‘ordinary lives in ordinary places’
* consider the potential for differentiation in the regulations between respite, emergency placement, and ordinary residential settings; and between large institutional settings and small community based designated centres. In considering differentiation of regulations appropriate to smaller designated centres, the National Disability Authority advises that the regulations should be consistent with the policy set out in **Time to Move on from Congregated Settings,** which is clear, that housing for people with disabilities in the community, should have no more than **four** residents
* consider the need for supporting guidance on the interpretation of certain regulations in practice, particularly when applied to different types of residential settings
* include an overall review of the role of the person in charge taking account of the diversity of different settings in disability services, from large centres to small group homes and individual living arrangements. Such a review should consider each regulation and the appropriateness of whether the responsibility for compliance should be with the person in charge or the registered provider

An additional advantage of carrying out a consultative review process would be the opportunity to raise awareness and enhance the understanding of disability service providers of their legal responsibilities and accountability under the regulatory framework.

## 4.2 Commentary on Specific Regulations

In the course of the National Disability Authority’s review, a number of issues were highlighted in relation to, the regulations for disability residential services. In some cases, specific regulations were identified and, in other cases more general points were highlighted by different participants in the review. The National Disability Authority has identified a number of regulations below that relate to these issues.

The specific regulations are listed under the two separate headings of the registration regulations and the care and support regulations.

The specific regulations and detailed commentary can be found in Appendix 1 of this paper.

## 4.3 Registration of Designated Centres for Persons (Children and Adults) with Disabilities Regulations 2013, S.I. No. 366 of 2013

Issues were raised with regards to the following registration regulations :

* Regulation 5(4), Application for registration or renewal of registration
* Regulation 8, Applications by registered providers for the variation or removal of conditions of registration and
* there is no allowance provided for in the Regulations for emergency placements

## 4.4 Care and Support of Residents in Designated Centres for Persons (Children and Adults) with Disabilities Regulations 2013, S.I. No. 376 of 2013

Issues were raised with regards to the following care and support regulations:

* Regulation 4, Written Policies and Procedures
* Regulation 5, Individualised Assessment and Personal Plan
* Regulation 8, Protection
* Regulation 9, Residents’ rights
* Regulation 11, Visits
* Regulation 12, Personal Possessions
* Regulation 14, Person in Charge
* Regulation 16, Training and Staff development
* Regulation 18, Food
* Regulation 27, Protection Against Infection
* Regulation 28, Fire Precautions
* Regulation 29, Medicines and pharmaceutical services
* Regulation 34(1)(d), Complaints Procedure
* Schedule 6, Matters to be provided in premises of designated centres.
* Schedule 6, no reference to single bedrooms

# 5. Residents’ rights

## 5.1 UN Convention on the Rights of Persons with Disabilities

The rights of residents are articulated in both domestic legislation and policy, as well as, in international conventions, such as, the **UN Convention on the Rights of Persons with Disabilities.** In addition to Article 19, previously outlined, a range of other articles have relevance to adults and children with disabilities living in residential settings and include rights, such as:

* Respect for dignity; non-discrimination; participation and inclusion; respect for difference; equality of opportunity; accessibility; equality between men and women; and respect for children (Article 3)
* Children with disabilities have the same human rights as all other children. The best interests of the child must be a primary consideration in all actions concerning children with disabilities. Children with disabilities have the right to express their views on all matters affecting them (Article 7)
* People with disabilities have the right to access all aspects of society on an equal basis with others including the physical environment, transportation, information and communications, and other facilities and services provided to the public (Article 9)
* People with disabilities have the right to liberty and security of person on an equal basis with others. Existence of disability alone cannot be used to justify deprivation of liberty ( Article 14)
* People with disabilities have the right to be free from torture and from cruel, inhuman or degrading treatment or punishment. No one shall be subjected to medical or scientific experimentation without his or her free consent (Article 15)
* People with disabilities have the right to be protected from all forms of exploitation, violence and abuse, including their gender based aspects, within and outside the home (Article 16)
* Every person with disabilities has a right to respect for his or her physical and mental integrity on an equal basis with others (Article 17)
* **Living independently and being included in the community(as cited above)** **(Article 19)**
* People with disabilities have the right to express themselves, including the freedom to give and receive information and ideas through all forms of communication, including through accessible formats and technologies, sign languages, Braille, augmentative and alternative communication, mass media and all other accessible means of communication (Article 21)
* People with disabilities have the right to privacy. Information about people with disabilities including personal information and information about their health should be protected (Article 22)
* People with disabilities have the right to an adequate standard of living including food, water, clothing and housing, and to effective social protection including poverty reduction and public housing programmes (Article 28)
* People with disabilities have the right to take part in cultural life on an equal basis with others, including access to cultural materials, performances and services, and to recreational, leisure and sporting activities (Article 30)

## 5.2 Residents’ rights

The National Disability Authority acknowledges that HIQA does inspect against Regulation 9 – Residents Rights, as well as, looking at rights in the context of safe practices and premises; residents exercising choice; advocacy etc.

In exercising rights what is also important is how the voice of residents is heard and how they are supported in having that voice heard, in relation to their rights.

People living in designated centres raised a number of issues, in the course of the National Disability Authority’s review, about the HIQA inspection process in their homes. The rights to information/communication; consent and privacy were highlighted as follows:

* Residents want information and education about the HIQA inspection process and want to be consulted about it
* Residents want to communicate with inspectors
* Inspectors’ engagement with people who are non-verbal or who communicate in different ways is important
* Fear was an issue for residents in relation to inspections, partly because of a lack of information and partly because of staff ‘frightening’ residents about the outcome of inspections if they communicated complaints or concerns to the inspector
* The issues in ‘Áras Attracta’ also causes concern for residents who are not directly involved
* Getting consent from residents during inspections is important particularly in relation to accessing bedrooms; accessing personal files and information; and contacting family members
* Residents reported a lack of information on inspection reports and action plans
* Residents reported a range of positive and negative outcomes of inspections. For example, positive outcomes included changes in staffing levels and increased access to advocacy and supports. Negative outcomes included, for example, more house rules and the need for the house to be clean at all times
* People with disabilities want to be involved in inspections

## 5.3 Engagement with the HIQA process

The recommendations made by residents related to the following:

* consultation with people with disabilities
* information and education

### The recommendations in relation to information and education are divided into things people recommend happens: Before an inspection visit

* People would like notice of inspections. If an inspection is announced, people would like notice of the visit. People expect their service provider or HIQA to tell them (two weeks before would be good)
* HIQA should send the name and a photo of the Inspector(s) who will be visiting

### During an Inspection visit

* inspectors should have an ID badge so people know who they are

inspectors should talk with people with disabilities first before meeting managers

### After an inspection visit

* Everyone should get a copy of the report and know what will happen next.
* people may need support to read and understand the information
* People would like a meeting with the inspector after the visit to talk about what they found and talk about the changes they suggest. People wished to have the option of refusing some changes in their homes
* People should have an opportunity to put their ideas into the action plan that service providers develop. The actions taken affect people’s home and lives, and they should have a chance to put their suggestions forward

### Meeting the inspector

* Inspectors should have training and experience in working with people with intellectual disabilities. They should get information about how people communicate and how to support people who communicate in different ways, for example Lámh
* Inspectors should have a set of pictures and photographs which they can use to talk to people
* Inspectors should allow plenty of time to make sure they talk to everyone. It’s important to give extra time to people who communicate in different ways
* Inspectors should be kind, friendly and make people feel comfortable
* Everyone in the house should have a chance to talk to the inspector and to have their say
* People should be given the choice to meet the inspector alone or with support. If they require support, they should choose who will support them – family, friend, staff, advocate etc.
* Inspectors should not assume that people have been given the opportunity to talk to them by the staff or service providers. They should check this with each resident themselves
* If residents are out of the house when the inspection is on, the inspector should come back at a different time. The inspector should make sure everyone who wants to talk to them can
* Inspectors should share a meal or a cup of tea with residents and chat
* Inspectors should tell people whether what they say will be kept private or shared with a service provider or staff. If information is going to be shared with the service provider or staff, residents need to understand that this will happen, how and the reasons why

### Consent

Consent should be sought from the person about accessing files, entering bedrooms, involving families and talking with an inspector.

The opportunity should be offered to residents to accompany inspectors while they look at the person’s bedroom or files.

if a person does consent to their family being involved, the person should choose which family member gets involved.

### The inspection team

It would be helpful to have a published plan of action for HIQA engagement with residents. Residents were keen to be part of the process including in some cases, being part of an inspection team. Suggestions from residents included comments, such as:

“People with disabilities, who are experts by experience, should be on the HIQA Inspection team.”

“We have very valuable knowledge. We also have a unique view on the day to day running of a residential house, and the issues that are important to people living there.”

“Send someone like us and pay us like in England. People living in services will listen to us – we are their peers and they are ours. I know what it’s like – it’s like a jail without bars. We live it day in and day out.”

“There should be at least 3 people with learning disability on the inspection teams. They could meet residents as a focus group and share their experience. One person’s view in an inspection team could be easily outweighed.”

”Inspectors with a learning disability could meet people before the other inspectors. This would show that the person whose home is being inspected have important views that must be taken seriously. This would send out an important message to support staff and the organisation that people with a learning disability have an important role to play in this official government sponsored team.”

“People with disabilities may have a role in providing support to people who communicate in different ways”.

### Advice

8. A specific awareness programme should be developed by HIQA and the HSE, in consultation with residents, regarding education and information to address the deficits outlined in the review in relation to, such things as:

* Lack of awareness among residents about who HIQA is and what it does
* Why there are inspections
* What happens during an inspection
* How residents can be involved
* How privacy and consent will be dealt with

9. The HSE, in consultation with service providers and residents, should develop staff protocols regarding good practice for staff engagement with residents in relation to HIQA inspections. This good practice should also be informed by such things as the rights of residents. Service provider organisations should ensure that such protocols are being implemented within each designated centre operated by them.

10. HIQA should advise in relation to the development of protocols with residents in relation to consent – for accessing personal files; entering individual’s bedrooms; engagement with significant others, like family members and the residents engagement with inspectors.

11. Ensuring the voice of residents gets heard through developing and introducing supports in services, such as:

* HSE supporting the development of residents forums and the role played by other residents with experience in supporting the establishment of such forums
* Service providers facilitating access to and engagement with independent advocacy services, in line with the individual residents choice and needs
* HIQA establishing mechanisms for effective feedback from residents, such as, independently commissioning annually, residents views of HIQA inspections and publishing the feedback

# 6. HIQA

## 6.1 The inspection process

Every person interviewed recognised and welcomed the need for regulation and inspection in the disability sector. The need for inspections to cater to people with a huge spectrum of abilities and needs in different settings was recognised as a challenge in the disability sector.

A number of issues arose with service providers with regards to:

* The perceived lack of consistency both in terms of the inspectors approach to particular issues and interpretation of Regulations
* Apparent variance across different HIQA regions
* HIQA inspectors covering both Nursing Homes and Disability Residential services

### Advice

12. HIQA should reconfigure the inspector team structure to have one group inspecting older person's services and a different team of inspectors for disability services.

## 6.2 Verification processes used by HIQA

The National Disability Authority acknowledges the importance of having a robust verification process within a Regulatory Framework and the importance of up to date documentation in this process.

HIQA have acknowledged same, as well as, other elements that are used to inform a judgement, such as, observation by inspectors in the course of inspections; notification of incidents; reports etc

Some service providers, however, did highlight the perception that the HIQA inspection is primarily “a paperwork” exercise. Other stakeholders stressed the need for more engagement by HIQA with third parties who are involved with the residential service, such as, advocacy services, family members and significant others. This potentially could provide for a more rounded verification process.

### Advice

1. HIQA should review their current process for engagement with third parties in residential services for people with disabilities with a view to identifying how such engagement could be enhanced as an integral part of the inspection process and contribute to the validation/verification process.

## 6.3 Ongoing training for HIQA inspectors

A number of issues were raised by service providers with regards to the HIQA inspectors understanding and knowledge of disability. The views of the HIQA interviewees were consistent in relation to the value of ongoing training. All were supportive of this and a number of potential subject areas were identified:

* A total communication approach for engaging and consulting with people who communicate in different ways to ensure those who communicate differently could be supported in getting their thoughts across
* Understanding behaviour, assessing the management of behaviour and the identification of positive behaviour supports
* Restrictive practices
* Capacity and consent
* Financial management
* Advocacy

### Advice

1. HIQA develops an agreed programme for ongoing training in the key areas identified above. In addition, the National Disability Authority suggests that ongoing training should also include, such topics as:

* Awareness and understanding of disability policy (for example, **New Directions; Time to Move On; Comprehensive Employment Strategy**)
* Alternative models of support for independent living

1. HIQA should publish what ongoing training and guidance was delivered for inspectors of disability services in any given year in their Annual Report and identifying any challenges that may have arisen.

## 6.4 Developing action plans

The inspection report includes an action plan where the service provider is asked to state how they will address areas of non-compliance. This plan can be accepted or rejected by the inspector if they feel the actions are not sufficient to rectify the issues of non-compliance in a timely manner.

Service providers are given two weeks and a number of opportunities (usually two) to revise the action plan or specific components of the plan to meet the requirements. Some inspectors will engage with service providers face to face, by email or by phone to support them with this process. Some HIQA staff commented on the “inordinate” amount of time spent with some service providers in disability settings in order to facilitate the development of action plans. The HIQA interviewees noted that inspectors are “supportive” but “not prescriptive”, and must “be mindful of their role as a regulator and in this regards cannot assume the role of consultant or manager”. Inspectors are aware of that there will be a different ethos in different service providers and the HIQA interviewees suggested that inspectors “allow the provider flexibility in how they address certain issues”.

The issues that may lead to action plans being rejected were identified by the HIQA interviewees as:

* inappropriate timelines
* lack of detail
* inadequate measures taken to deal with issues of non-compliance
* inadequate information provided
* actions not SMART (Specific, Measurable, Achievable, Realistic, Timely)

Most service providers described how the plans are worked on by the Person in Charge at the local level initially, often with support from senior managers in relation to timelines or resources. More serious issues or those with significant financial implications are escalated to the CEO, provider nominee or an area/service manager.

The Persons in Charge remarked on the wide range of people they liaise with in the development of an action plan. These include senior managers, clinicians, and departments such as quality; governance; finance; HR; buildings and maintenance; health and safety.

Service providers and other stakeholders highlighted the challenges involved in developing action plans. These include:

* Feeling under pressure to solve long term or complex problems in a very short time period and agreeing realistic timelines with HIQA
* Developing organisational policies in a short space of time
* Establishing working groups or multi-disciplinary team supports in a short period of time – this can be necessary to identify appropriate actions and agree the long term implementation of the plan
* Managing costs and resources within existing budgets
* Feeling under pressure to invest in congregated settings which are due for closure
* Sourcing the correct documentation and evidence for submission with the action plan
* Managing issues of conflict between the inspectors and the Persons in Charge and service providers
* Communicating between HIQA and service providers can sometimes be poor, for example, mislaid documentation, contradictory information

In a number of interviews, participants raised the question of the involvement of the HSE (as the funder), at this stage of the inspection process. The HSE noted that they do not get involved in the development of action plans with non-HSE providers, as the service providers, as they are “private companies in their own right”. The HSE acknowledged that it can be in an awkward position as they engage with HIQA as both funder and provider of services.

The National Disability Authority is conscious of the separate legal responsibilities involved with various stakeholders. However, clarity needs to be brought to the action planning process that ensures quality outcomes for residents and delivers any compliance issues within limited resources and that is in line with national policy.

The National Disability Authority is aware of the HSE Quality Improvement Team playing an important role in supporting HSE service providers and finding out what is actually happening on the ground in those services and making recommendations to bring about a more coherent and improved quality of services across the HSE. The National Disability Authority believes there are opportunities here for shared learning beyond the HSE services to service providers across the sector. This could support a more responsive approach by all service providers in continuing to improve the quality of services for residents.

### Advice

1. Building on the experience of the HIQA inspections to date; the HIQA Judgement and Assessment Framework, service providers should conduct an audit of their services with a view to

* Examining the adequacy of the quality of service they are currently providing to residents
* Identifying any potential/actual gaps in service provision
* Exploring alternative ways of addressing such gaps
* Quantifying any resource issues

1. The HSE would develop guidance on how to carry out action planning post a HIQA inspection. The guidance should include:

* The legal context
* Clarification on the roles and responsibilities of HIQA; HSE; Service Provider in the context of action planning
* Process for addressing issues that may require the commitment of additional resources, such as, recruiting additional staff
* How resources should be targeted at priority areas
* Who service providers can contact for advice

1. Building on the experience of the SCD/QID Quality Enablement Programme the HSE examine the potential for the development of national protocols and shared learning opportunities across all residential services and expand SCD/QID Quality Enablement Programme beyond HSE services only.

## 6.5 Action plans and staffing issues

A number of issues arose in this context, which related to:

* The competency of the individuals managing the designated centre, in particular the Person in Charge
* Staffing levels
* Competencies and skills required to deliver quality residential services in line with Government policy
* Requirements for particular professionals, such as, nursing staff
* The attitude of and the approach taken by the management team

The National Disability Authority is of the view that there is a need for an agreed national competency framework for residential service for adults and children with disabilities. In the absence of same, there are many challenges for service delivery, which impacts on the quality of life for residents. It is not only a question of having additional staff but also of identifying what are the competencies and range of skills required by staff to deliver a quality residential service which best supports:

* individuals, across a spectrum of need, to achieve best outcomes for that person
* independent living
* positive risk taking
* people to live ordinary lives in ordinary places
* quality services in line with the Regulations and standards and national policy

### Advice

1. The Department of Health, through the implementation process for **Transforming Lives**, would task a group with evaluating good practice in residential settings in line with national policy and identify the skills; competencies; levels of support; staffing requirements; and enabling technologies that underpin good practice.
2. Informed by the findings of this group the Department of Health would oversee the development of a national competency framework for the delivery of quality residential services for adults and children with disabilities based on good practice.

### Nursing staff

Another particular issue that arose during the National Disability Authority’s review was the perceived requirement for qualified nursing staff. This emerged in feedback from some of the service providers in the context of medication management, care plans etc. The National Disability Authority is also aware that in some cases, individual residents are in need of particular medical care and it does raise the issue of how equipped a residential service is to provide such given that its primary focus is not a “nursing home”.

### Advice

1. The Department of Health establishes a working group to review the identified health and medical needs of people currently availing of disability residential services and make recommendations on how best they could be provided for. This Review should identify, inter alia,

* What the health needs of residents are
* How best these needs could be met, for example, through primary care; public health nurse; GP; multi-disciplinary team; dedicated nursing staff and/or other professional
* What is the most appropriate setting for the provision of these services to the individual’s concerned

# 7. Continuous quality improvement

## 7.1 Service provider initiatives

The National Disability Authority area aware of a number of initiatives undertaken by service providers to improve the quality of services they are delivering to people in residential services.

A number of these initiatives were dependent on the size of the organisation and the resources available to commit to quality improvement. Some service providers had quality improvement/excellence schemes in place prior to the commencement of HIQA inspections.

In the National Disability Authority’s analysis of HIQA reports, ownership type and membership of one of the umbrella organisations seemed to make a positive difference. In some cases the HSE and small non-profit organisations (mostly small charities) that are not members of either the Federation of Voluntary Bodies or Not for Profit Business Association seemed to have higher levels of non-compliance.

Since the commencement of HIQA inspections, sharing knowledge and expertise was highlighted by a number of service providers as key. During the interviews conducted by the National Disability Authority, participants highlighted the ways in which shared learning from the HIQA process could help ensure that services for people with disabilities are based on best practice. Service providers highlighted the benefits of “cross learning” in raising standards and in service development. Examples cited include:

* Service providers involved in the early registration process gave informative feedback to other stakeholders
* In-house meetings for Persons in Charge and managers: these involved staff from different designated centres within one large organisation, and in some cases they offered a ‘peer support’ system for Persons in Charge.
* Some groups undertook specific tasks such as analysing published reports for examples of good practice, exploring areas of non-compliance, training on new policies or gathering evidence in relation to policy development. Service providers highlighted the benefits of “cross learning” in raising standards and in service development
* Sharing information across different service providers and agencies: Some Persons in Charge and managers established informal and formal networks with other service providers in an attempt to share experiences
* A resource point was developed by an Umbrella Organisation on its website to facilitate the sharing of HIQA related policies and documentation

The National Disability Authority is of the view that continuous professional development should be a normal and mandatory part of staff working in residential services and is a critical component for effective services. There is a need for an agreed national approach to the promulgation and sharing of good practice among service providers

### Advice

1. HSE should develop a sustainable mechanism for shared learning and good practice. Such a model should include features such as:

* Expand the remit of the HSE Quality Improvement Team to cover services other than just the HSE
* Proportioning part of the annual budget specifically for CPD
* Making staff participation mandatory and part of service level agreements
* Monitoring and evaluating participation levels; follow through into changed practice etc, including feedback on practice in services from residents
* Improving interaction and sharing of expertise and learning between service providers

1. A specific training and education programme should be provided for Persons in Charge.

## 7.2 HIQA’s role

Service providers found events organised by HIQA were useful and helpful. It should be noted, that it is a little unclear from the interviewees, what HIQA’s role in relation to promoting good practice actually is. The views of the interviewees differed in this regard.

From the interviews conducted during the review, it appears some HIQA staff currently view their role to be ‘narrower’ than service providers and stakeholders may wish it to be. Their focus has been primarily on identifying issues of non-compliance, rather than highlighting examples of good practice. There would be value in facilitated shared learning based on the good practice identified by HIQA during the inspection process.

## Advice

1. The HSE, in consultation with HIQA, should consider the development of a new online portal for promoting good practice and this could also be informed by the work being conducted by the HSE Quality Improvement Team, as well as, the good practice HIQA encounters during the inspection process.
2. HIQA should produce an annual overview report of its findings from inspections and highlight good practice, which would be informative for the sector.

## 7.3 Thematic inspections

A number of participants suggested that the introduction of **thematic inspections** in the future would have a positive effect on the lives of people with disabilities, and it was noted that these inspections should encourage service providers to focus on issues which are important to people with disabilities.

### Advice

1. HIQA promote good practice through the process of thematic inspections of adult and children residential services. A key focus initially should be on Quality of Life Outcomes, and Person-centred Planning.

# 8. Leadership, culture and practice

## 8.1Good practice

The National Disability Authority in its engagement with HIQA identified the following elements of what contributes to good practice in residential services:

* a strong person centred approach which focuses on the individual, personal goals and “taking the person where they are at”
* responsive leadership in organisations who act quickly; appropriately and show a willingness to change
* competent Person in Charge that is, well trained, experienced, aware of their role, knows the residents well
* outcomes focussed
* organisation and staff are motivated to improve the quality of life of residents
* quality engagement with residents – residents participating in purposeful activities
* residents are involved in their local community
* quality interactions between residents and staff
* good communication supports
* staff trained and supported to deal with behaviours that challenge
* care plans of a high standard
* a social, rather than, medical model
* access to self-advocacy and independent advocacy services
* service providers who are responsive and willing to change
* competent staff who are well supported and have access to ongoing training and up-skilling

## 8.2 Leadership, culture and practice

To bring about the proposed changes and the future direction of residential services for people with disabilities it requires active leadership to drive the required change. Leaders need to understand the needs of people with disabilities who are in residential services and direct the resources to provide person centred services.

Changing the culture and practice in organisations involves having supported and accountable staff who actively engage with residents. It is having staff who are motivated and who are responsive to residents in supporting them to be engaged in meaningful activities.

The National Standards for residential services emphasises that service users needs and preferences must be at the core of all services provided and Theme 5 of the standards on leadership, governance and management stresses the importance of leadership in achieving this.

It is the National Disability Authority’s view that such change does not come about by chance. Rather, managers at all levels need to be proactive in supporting staff and specifying the activities that give the outcomes desired by residents to have a quality of life.

### Advice

1. All residential service providers should have clear systems of communications between management, staff, residents and family members.
2. Residents should be proactively engaged with by managers in providing feedback and contributing to the improvements of services provided.
3. HSE should ensure that adequate training and development opportunities should be provided to staff in all residential services and a monitoring system established to verify this has been done and implemented in practice at local level.
4. HSE, building on the experience and information gathered from both the HSE Service Improvement Team and the Quality improvement Enablement Programme should analyse and address organisational culture issues that impact on leadership and practice and the quality of life for residents.

Summary Table of Advice

The following table summarises key areas of advice and who should be the lead body in relation to progressing same. A reference advice number is provided to where more detailed commentary can be found in the advice paper.

| Key advice | Key areas include | Lead | Advice reference no. |
| --- | --- | --- | --- |
| Examination of Primary Legislation | * definitions * registration of centres * care of residents if registration is cancelled * implications of Assisted Decision Making (Capacity) Act 2015 | Department of Health | 1-3 |
| Review of regulations | Conduct a comprehensive review of the current regulations | Department of Health | 7 and Appendix 1 (31-49) |
| Ensuring Residents’ Rights are upheld | * awareness of HIQA and inspection process * residents are communicated with appropriately * giving consent * right to advocacy | HIQA and HSE have lead roles in relevant areas | 8-11 |
| Reviewing HIQA inspection process | * Dedicated inspection teams for disability services * 3rd party verification processes * Ongoing training for inspectors | HIQA | 12  13  14,15 |
|  | * Service provider audits * Guidance on Action planning * Developing national protocols and shared learning mechanisms | Service providers  HSE | 16  17  18 |
| Promoting good practice | * Transforming Lives- tasking a group to identify good practice * Developing a national competency framework * Reviewing the medical needs of residents and identifying good practice in this area | Department of Health | 19  20  21 |
| Promoting good practice | * Implement advice to HSE-run services of Quality Improvement Team * Establishing a Sustainable mechanism for shared learning * Developing an appropriate training and education programme for Persons in Charge * Establishing an online portal for good practice * Annual report of HIQA findings and highlighting good practice * Thematic inspections with key focus (initially( on: * Quality of life outcomes * Person centred planning | HSE  HSE. Service Providers have lead roles in relevant areas  HSE  HIQA  HIQA | 4  22  23  24  25  26 |
| Leadership, culture and practice | * Clear communication systems for management, staff and residents * Proactive and meaningful engagement with residents * Implementation mechanisms to ensure learning is transferred into local practice * Addressing organisational structure that impacts on leadership and quality of life of residents | Service providers and HSE have lead roles in relevant areas | 27  28  29  30 |
| In the longer-term, establishing a Commissioning Process | * Having an agreed Commissioning framework in place * Commissioning process should include: * Assessment of need * Service priorities/goals * Outcomes * Monitoring and evaluation | HSE | 5-6 |

Appendix 1

# Advice on specific regulations

## A.1 Commentary on Specific Regulations

In the course of the National Disability Authority’s review, a number of issues were highlighted in relation to the regulations for disability residential services. In some cases, specific regulations were identified and in other cases, more general points were highlighted by different participants in the review. The National Disability Authority has identified a number of regulations in the commentary below that relate to these issues.

The National Disability Authority’s recommendation is for a comprehensive review of the regulations as a whole, however, the commentary below highlights some specific regulations that presented challenges.

The comments on specific regulations are listed under the two separate headings of the registration regulations and the care and support regulations.

## A.2 Registration of Designated Centres for Persons (Children and Adults) with Disabilities Regulations 2013, S.I. No. 366 of 2013

For readability purpose, these regulations are referred to in the text as the ‘registration regulations’.

### A.2.1 Registration Regulations, Regulation 5(4), Application for registration or renewal of registration

Regulation 5(4) states that the fee to accompany an application for the registration or the renewal of registration of a designated centre under section 48 of the Act is €500. This fee is per designated centred, notwithstanding the number of residents. Separate annual fees payable under Regulation 9 are based on a cost per resident..

Under this regulation, smaller community based designated centres would incur higher costs than those running larger designated centres. For example, a large setting with say 21 residents would have a registration fee of €500, while 7 smaller residential services with 3 residents in each would cost €3,500.

### Advice

1. The fee structure under regulation 5(4) in the registration regulations should be revised to ensure that providers running smaller community based designated centres are not at a financial disadvantage when compared to providers of larger designated centres, including congregated settings, which national policy dictates should be closed down.

#### A.2.2 Registration Regulations, Regulation 8, Applications by registered providers for the variation or removal of conditions of registration

Section 52(1) of the Health Act allows for a registered provider to apply to the chief inspector for the variation or removal of any condition of the registration of the designated centre. Section 52(3) of the Health Act says that an application made under Section 52(1) shall be accompanied by the prescribed fee. Regulation 8 of the registration regulations sets out the fee for application for the variation or removal of conditions of the registration of a designated centre:

The fee to accompany an application in accordance with section 52(3) of the Act for the variation of a condition of registration is—

(a) €100 for the minor variation of a condition of registration; and

(b) €500 for the major variation of a condition of registration

The costs associated with making changes to registration details was raised by service providers during the review.

It appears this fee structure may disadvantage providers of smaller community based designated centres who because of the nature of their services will have a greater number of separate registrations and may therefore need to apply for a greater number of variations than providers of larger congregated settings.

Section 52(4) of the Health Act 2007 allows for different fee amounts to be prescribed for different circumstances or different categories of designated centres, so it appears that there is scope in the regulation for this issue to be addressed.

### Advice

32. Revising the fee structure under Regulation 8 of the registration regulations should be considered, to ensure that providers running smaller community based designated centres are not at a financial disadvantage when compared to providers of larger designated centres including congregated settings, which national policy dictates should be closed down.

#### A.2.3 Registration Regulations, no allowance for emergency placements

A specific difficulty that was highlighted in the National Disability Authority’s review is how registered providers are to comply with regulations in the case of emergency admissions. This is because of the requirement that a new designated centre must be registered before a residential service can be provided. There is a perception that the regulations are ‘too strict’ and ‘very rigid’ in this regard. Provider nominees describe the extreme consequences of breaching regulations, including large fines, court cases and jail sentences, when often they have to act immediately to deal with crisis situations. The lack of spare capacity in residential services exacerbates this problem.

Managers and CEOs explained that they have had to open houses; admit individuals without adequate assessment; move residents from one house to another at short notice; move residents to new buildings, which are not registered – all in response to emergencies, but all against the regulations. One person in charge explained that they have stopped offering emergency respite/placements as it raises too many potential issues of non-compliance.

The National Disability Authority is of the view, that there is a need for the HSE to enhance its systems for identifying long term needs of individuals with disabilities and examining ways to maximise the potential for supporting those individuals remain in their own homes, for example following the death of a parent, thus reducing the need for emergency type placements.

There is also a need to review the current requirements of the regulations and how best emergency placements should be addressed.

### Advice

1. The issue of emergency placements and whether there is a need to make special provision for same should be considered as part of a review of the regulations, with due regard to the need for quality and safety of services in such placements. The HSE should review its current policy and practice of emergency placements and in particular any inappropriate placements, such as placing people with disabilities in nursing home settings, who do not require nursing care.

The National Disability Authority would also deem the emergency placement of a person in a congregated setting as unacceptable. Alternative contingency plans should be put in place, and this practice should cease.

## A.3.3 Care and Support of Residents in Designated Centres for Persons (Children and Adults) with Disabilities Regulations 2013, S.I. No. 376 of 2013

For readability purposes, these regulations are referred to in the text as the ‘disability care and support regulations’.

### A.3.1 Care and Support Regulations, Regulation 4, Written Policies and Procedures

Regulation 4(1) requires the registered provider to adopt and implement policies and procedures in a range of areas set out in Schedule 5 of the regulations. In the review, service providers submitted that there was a lack of clarity in the interpretation of the regulations regarding the use of a single national policy versus a site specific policy.

Regulation 4(3) states that the registered provider shall review the policies and procedures referred to in paragraph (1) as often as the chief inspector may require but in any event at intervals not exceeding 3 years and where necessary, review and update them in accordance with best practice. It was commented in the review that there was a lack of clarification on how often policies should be reviewed.

### Advice

1. A review of the regulations should include consideration of the clarity of Regulation 4 in the care and support regulations and whether guidance is required to provide clarity on interpretation of this regulation.

#### A.3.2 Care and Support Regulations, Regulation 5, Individualised Assessment and Personal Plan

Regulation 5(1) requires the person in charge to ensure that a comprehensive assessment of the health, personal and social care needs of each resident is carried out prior to admission to the designated centre. Regulation 5(4) requires the person in charge to, no later than 28 days after the resident is admitted to the designated centre, prepare a personal plan for the resident.

There are a number of issues to be considered in relation to this regulation:

* Some people may have been living in a designated centre for a number of years prior to the introduction of the regulations and may not have had an assessment carried out prior to admission as required under regulation 5(1)(a). It appears that that it would not be possible to comply with this section of the regulation if an assessment had not been carried out prior to admission
* It was noted that some people who use residential services don’t want a personal plan. This is provided for in the standards, but not in the regulations; feature 2.1.8 of the standards states ‘Where a person declines to engage in the planning process, the person in charge ensures that arrangements are made to address their needs as identified in the assessment and their aspirations and wishes insofar as these can be ascertained. A record is kept of all attempts to engage people and their representative in the planning process’
* It was noted that it may not be appropriate or relevant for a respite service which by its nature caters for people for a limited time, to develop personal plans for each person using their service. For example, the definition of a personal plan in the standards refers to a person’s personal development goals in the area of education. Education goals may not be relevant to the service provided by a respite service, which by their nature cater for people for a short period of time It may be more appropriate for respite services to have regard to any such person-centred plan already in place, or it may be more appropriate to have a ‘respite plan’ in place that covers the activities and supports an individual will benefit from during successive respite stays,
* Regulation 5(4) appears to place emphasis on the development and review of a personal plan, but not its implementation to the same extent. The implementation of personal plans is key in relation to the services a person uses, and how these can support positive change in their quality of life

This regulation refers to the development and review of ‘personal plans’. In discussing this regulation during the review, interviewees used different terms including ‘care plan’ and ‘person-centred plan’. Care plans and person-centred plans are two different types of plans commonly used in disability services. A care plan may also be called a support plan and is about meeting a person’s everyday needs. A person-centred plan is about a person’s vision for their life, and may refer to broader quality of life issues such as relationships, education and employment. The term ‘personal plan’ is used in the regulations, which is defined as a plan prepared in accordance with Regulation 5(4). The National Disability Authority notes that there is confusion in the disability sector with the term “personal plan” and some see it as person centred planning; others as care plans or support plans etc. Clarity needs to be brought to this in the review of the regulations.

### Advice

1. Regulation 5 in the care and support regulations should be reviewed in light of the range of issues raised in the National Disability Authority’s review, as outlined above.

### A.3.3 Care and Support Regulations, Regulation 8, Protection

Regulation 8(3) states that the person in charge shall initiate and put in place an investigation in relation to any incident, allegation or suspicion of abuse and take appropriate action where a resident is harmed or suffers abuse. The National Federation of Voluntary Bodies submitted it should be the registered provider, rather than the person in charge who should undertakes investigations under this regulation.

### Advice

1. The responsibility of the person in charge under Regulation 8(3) in the care and support regulations should be considered as part of an overall review of the role and responsibilities of the person in charge.

#### A.3.4 Care and Support Regulations, Regulation 9, Residents’ rights

Regulation (2)(a) requires the registered provider to ensure that each resident, in accordance with his or wishes, age and the nature of his or her disability – participates in and consents, with supports where necessary, to decision about his or her care and support. The National Federation of Voluntary Bodies asked for clarity in relation to this regulation around consent if no next-of-kin exists.

### Advice

1. The impact of the Assisted Decision Making (Capacity) Act 2015should be considered in a review of the regulations, particularly, the care and support, residents’ rights regulations.

#### A.3.5 Care and Support Regulations, Regulation 11, Visits

Regulation 11(3)(b) in relation to visits, requires that a suitable private area, which is not the resident’s room, to be available to a resident in which to receive a visitor if required. The National Disability Authority notes that this particular regulation is a good example of the difficulties in having “ a one size fits all” approach. It is easy to imagine that an ordinary home with kitchen, dining and living spaces might provide adequate visiting arrangements, where they are shared by a small group of say 3 people who have chosen to live together and who would be in a position to agree arrangements within their home for visitors. In residential settings with larger numbers of residents, the requirement in this regulation for additional private areas for people to meet with visitors could be considered a reasonable requirement.

### Advice

1. A revision of regulation 11(3)(b) should be considered to differentiate between smaller houses in the community and larger settings where a private area for visitors would be necessary because of the number of residents.

### A.3.6 Care and Support Regulations, Regulation 12, Personal Possessions

Regulation 12(4) sets out requirements in relation to residents bank accounts. In the review, the HSE indicated that there is a discrepancy between HSE and HIQA guidance (based on the regulations) on how residents’ finances should be managed.

#### Advice

1. The HSE guidance on managing residents’ finances needs to be reviewed and made compatible with the regulations.

#### A.3.7 Care and Support Regulations, Regulation 14, Person in Charge

Regulation 14(2) states that the person in charge is a full time post. In the review, the National Federation of Voluntary Bodies noted that the requirement that a Person in Charge should work full time is challenging, restricts organisations in terms of who they can appoint, and in instances is at odds with employment law entitlements, for example, the entitlement for staff to avail of parental leave.

Regulation 14(3) states that the person in charge shall have a minimum of 3 years experience in a management or supervisory role in the area of health or social are and an appropriate qualification in health or social care management at an appropriate level.

The National Disability advises that clarity needs to be brought to what is meant by an appropriate health or social care management. In some cases, this has been interpreted to mean a “nurse”, although in some cases there may not be a requirement to have a “nurse-led service”. Similarly, there is a perceived lack of clarity around what is meant by “full time post”. In this regards, the National Disability Authority is of the view that there is a need to provide guidance on this and what it means to have a person responsible and dedicated to a specific role as opposed to it being interpreted as a 24/7 full time and being on site at all times.

### Advice

1. The review of the Regulations should consider the appropriate roles and responsibilities for a Person in Charge in the context of a service model characterised by small group homes and, increasingly in the future, more individualised arrangements; and consider what elements of the current role should reside with senior or area management, and what with house managers.

### A.3.8 Care and Support Regulations, Regulation 16, Training and Staff development

This regulation requires the person in charge to ensure that staff has access to appropriate training, including refresher training.

The National Disability Authority sees the issue of appropriate training of staff and ongoing continuous professional development as a critical issue. There appears to be large variation in the duration, frequency and content of training programmes and in the manner in which learning is then put into practice, monitored and evaluated.

### Advice

1. In the context of Regulation 16, guidance should be provided to give clarity on the requirements of the care and support regulations, in order to ensure consistent interpretation and application across the sector.

#### A.3.9 Care and Support Regulations, Regulation 18, Food

Regulation 18(2)(a) requires the person in charge to ensure that each resident is provided with adequate quantities of food and drink which are properly and safely prepared, cooked and served. In the National Disability Authority’s review, the HSE reported that HACCP / institutional standards of food hygiene were required by HIQA in a domestic scale kitchen in a community dwelling. The standards of food hygiene appropriate in a kitchen catering for a large number of residents are likely to be different to those for a domestic style kitchen in a home for a small number of residents.

### Advice

1. Guidance should be provided on the interpretation of Regulation 18 in the care and support regulations, for different types of settings, which, also provides for the range of supports, in terms of education and awareness, an individual may need, who would be engaging in a range of independent living activities, such as, doing their own shopping ; cooking for themselves; levels of hygiene and others.

#### A.3.10. Care and Support Regulations, Regulation 27, Protection Against Infection

Regulation 27 requires the registered provider to ensure that residents who may be at risk of a healthcare associated infection are protected by adopting procedures consistent with the standards for the prevention and control of healthcare associated infections published by HIQA.

The National Standards for the Prevention and Control of Healthcare Associated Infections (HCAIs) published by HIQA state that the principles for the prevention and control of HCAIs are applicable to all health and social care services, including acute care services, community care services including dental services, primary care services, and across all sectors – public, voluntary and independent.

In this review, the National Disability Authority notes that the interpretation of the regulations was being perceived as ‘institutional’ requirements being applied in community houses for example segregated cleaning equipment and duties in keeping with institutional / clinical care standards as opposed to what would be “normal” in a person’s own home.

### Advice

1. The appropriateness of Regulation 27 in the care and support regulations being applied in small community houses should be considered in the review.

#### A.3.11 Care and Support Regulations, Regulation 28, Fire Precautions

Regulation 28 in the disability care and support regulations deals with a range of fire safety requirements. It was one of the top ten regulations breached by service providers when inspected against.

In the review, service providers raised concerns that the implementation of fire regulations applicable to designated centres is turning homes into ‘public buildings’ or ‘institutions’. It was commented that ordinary houses in the community do not need emergency lighting, nor fire procedures to be displayed in a prominent place, which are requirements under this regulation. While these may be appropriate in larger settings, it was commented that fire safety standards for institutions are being applied to ordinary houses in the community.

This issues relating to fire safety are broader than the disability care and support regulations. The National Disability Authority understands that the application of institutional fire safety standards to domestic scale housing also arises from the purpose group definitions in Part B of the Building Regulations with houses for people with disabilities, notwithstanding their scale or level of occupancy, being considered to come under the purpose group Residential (Institutional)2(a):

“Hospital, nursing home, home for old people or for children, school or other similar establishment used as living accommodation or for the treatment, care or maintenance of people suffering from illness or mental or physical disability or handicap, where such people sleep on the premises”.

The National Disability Authority has previously advised the Minister for the Environment, Community and Local Government that consideration be given to revising the purpose groups in the **Building Regulations** to include fire safety requirements appropriate to domestic-scale dwellings for people with disabilities living in the community. We have been concerned that institutional fire safety standards which may not be appropriate to domestic-scale housing for people with disabilities have been applied in situations where this is not necessary for the occupants’ safety and with unintended side-effects. It can create an institutional atmosphere in a person's home, contrary to the philosophy of 'ordinary homes in ordinary places'. There can also be a significant cost in upgrading to meet institutional fire safety standards in domestic dwellings. It can limit the range of properties to rent that are available for people with disabilities. It also adds complexity to the use of temporary accommodation which a person might use while their home is being renovated and therefore needs to have fire safety upgrades in order to be registered as a designated centre.

The National Disability Authority welcomes that a Working Group convened by the HSE is proposing a new building type which for the purposes of the building regulations will be considered a type of dwelling (rather than an institution), called a ‘Community Dwelling’. National Disability Authority understands that HIQA and the Department of the Environment are represented on this Working Group and that a Code of Practice for Fire Safety in New and Existing Community Dwellings is being developed and will be issued for consultation in early 2016. There are a number of issues to be considered in relation to the detailed content of this Code of Practice, including, how a ‘Community Dwelling’ is defined.

### Advice

1. A review of regulation 28 to ensure that appropriate fire safety measures are being applied to designated centres of different scales should be considered in light of the proposed ‘Code of Practice for Fire Safety in New and Existing Community Dwellings’ when this is finalised and agreed with the Department of the Environment.

The National Disability Authority in its advice to the Working Group examining this Code stated:

We have been concerned that institutional fire safety standards which may not be appropriate to domestic-scale housing for people with disabilities have been applied in situations where this is not necessary for the occupants’ safety and with unintended side-effects. It can create an institutional atmosphere in a person's home, contrary to the philosophy of 'ordinary homes in ordinary places'. There can also be a significant cost in upgrading to meet institutional fire safety standards in domestic dwellings. It can limit the range of properties to rent that are available for people with disabilities.

We understand that the definition proposed for the new Community Dwelling purpose group is for new and existing dwellings of up to six people and two carers. While we acknowledge that there are many legacy Community Group Homes that have more than four permanent residents, and that the new Code of Practice on Fire Safety, insofar as it refers to existing dwellings, should cover these, we advise that the provisions of the Code of Practice as they relate to new homes should be consistent with the policy as set out in **Time to Move on from Congregated Settings** (2011) that housing for people with disabilities in the community has no more than four residents. This policy reflects the strong international evidence that people living in larger group homes enjoy a poorer quality of life. We suggest that the definition of a house for four residents can include an additional room/accommodation can be made available for staff, house parent or volunteer to sleep over, where required, and where this person does not constitute one of the four residents.

It is important, that there is a consistency across different regulatory areas that promotes Government policy on smaller group homes, which is also in line with the principles of Article 19 of the **UN Convention on the Rights of Persons with Disabilities**. This is to ensure that policies do not serve to perpetuate the creation of 'mini-institutions' in the community.

#### A.3.12 Care and Support Regulations, Regulation 29, Medicines and pharmaceutical services

Regulation 29(4) requires the person in charge to ensure that the designated centre has appropriate and suitable practices relating to the ordering, receipt, prescribing, storing, disposal and administration of medicines. It arose in the National Disability Authority’s review that in some cases this was interpreted as meaning that a nurse is required to administer medicines, although the regulation does not state that. In the National Disability Authority’s review, one resident brought up this up in terms of a negative outcome of the inspection process; they described how some medications can now only be given by a nurse. If a nurse is not available to go on an outing then the person may need to stay at home to receive their medication from a nurse.

### Advice

1. The National Disability Authority is aware that regulations , of their nature, cannot be too prescriptive. However, in the review of the regulations consideration should be given to both medication management policies and appropriate and suitable practices.
2. Guidance on the interpretation of Regulation 29 with regards to the storage of medicines in different settings and the administration of medicines should be provided.
3. The HSE should develop a capacity assessment for residents to facilitate them self medicate, where possible. .
4. In addition, provision should be made for an independent review by a GP of the amount of medication an individual is prescribed and using

#### A.3.13 Care and Support Regulations, Regulation 34(1)(d), Complaints Procedure

Regulation 34 requires a registered provider to provide an effective complaints procedure for residents. This includes making residents and families aware of the complaints procedure.

Regulation 34(1)(d) requires the registered provider to display a copy of the complaints procedure in a prominent position in the designated centre. In the National Disability Authority’s review, this requirement was criticised as a regulation that reflects an institutional model of living rather than an ordinary home. It was commented that if a person is aware of a complaints procedure, and has a copy in a format accessible to them, the prescriptive requirement to display it prominently in their home is not necessary. It was also noted that in some cases, a person may not be able to read the complaints procedure on display in their home, so the regulation is not appropriate for some people who use residential services.

### Advice

1. As part of a review of the regulations, consideration should be given to the most effective means of communicating with and giving information to residents and their families about their right to make complaints and Regulation 34 should be revised as necessary to make provision for same.

### A.3.14 Care and Support Regulations, Schedule 6, Matters to be provided in premises of designated centres.

#### Schedule 6(4)

Schedule 6(4) requires ‘communal space for residents suitable for social, cultural and religious activities appropriate to the circumstances of residents’. The requirement for communal space of this nature suggests that a model where residents will be participating in segregated cultural and religious activities in the place that they live rather than engaging in these activities in the community, as would be in line with the national standards for disability services. Feature 1.4.2 of the national standards states ‘People are facilitated and encouraged to integrate into their communities. The service is proactive in identifying and facilitating initiatives for participation in the wider community, developing friendships and involvement in local social, educational and professional networks.’

#### Advice

1. The requirements of Schedule 6 of the care and support regulations should be reviewed to ensure that it aligns with the national policy and standards and does not reflect or support the provision of an institutional model of service provision. Prescriptive references should be removed to such things as religious, cultural activities. It is the National Disability Authority’s view that residents who choose to engage in cultural and/or religious activities should be supported to do so within their local community.

### A.3.15 Care and Support Regulations, Schedule 6, no reference to single bedrooms

Schedule 6 of the regulations sets out a range of requirements for matters to be provided in premises of designated centres. Schedule 6(1) requires adequate private and communal accommodation for residents, including adequate social, recreational, dining and private accommodation. In the national standards for residential services, under the standard requiring a person’s privacy and dignity to be respected, feature 1.2.2 states ‘each person has their own bedroom unless they wish to share.’ However, there is no requirement for single bedrooms in the regulations.

#### Advice

1. Given the clarity of feature 1.2.2 in the national standards, in reviewing the regulations, a requirement for single bedrooms in designated centres should be included unless an individual chooses to share a bedroom.

1. Page 8 **What constitutes a designated centre for people with disabilities?** HIQA, 2015 [↑](#footnote-ref-1)
2. New guidelines have issued end 2015 under the Capital Assistance Scheme which address this concern [↑](#footnote-ref-2)
3. **Supporting people’s autonomy: a guidance document,** Health Information and Quality Authority, January 2016. [↑](#footnote-ref-3)