Health Information and Quality Authority

An tÚdarás Um Fhaisnéis agus Cáilíocht Sláinte

Regulation of Health and Social Care Services

Five years of regulation in designated centres for people with a disability

July 2019

Safer Better Care

About the Health Information and Quality Authority (HIQA)

The Health Information and Quality Authority (HIQA) is an independent statutory authority established to promote safety and quality in the provision of health and social care services for the benefit of the health and welfare of the public.

HIQA's mandate to date extends across a wide range of public, private and voluntary sector services. Reporting to the Minister for Health and engaging with the Minister for Children and Youth Affairs, HIQA has responsibility for the following:

- **Setting standards for health and social care services** — Developing person-centred standards and guidance, based on evidence and international best practice, for health and social care services in Ireland.
- **Regulating social care services** — The Chief Inspector within HIQA is responsible for registering and inspecting residential services for older people and people with a disability, and children's special care units.
- **Regulating health services —** Regulating medical exposure to ionising radiation.
- **Monitoring services** — Monitoring the safety and quality of health services and children's social services, and investigating as necessary serious concerns about the health and welfare of people who use these services.
- **Health technology assessment** — Evaluating the clinical and cost-effectiveness of health programmes, policies, medicines, medical equipment, diagnostic and surgical techniques, health promotion and protection activities, and providing advice to enable the best use of resources and the best outcomes for people who use our health service.
- **Health information** — Advising on the efficient and secure collection and sharing of health information, setting standards, evaluating information resources and publishing information on the delivery and performance of Ireland's health and social care services.
- **National Care Experience Programme** — Carrying out national service-user experience surveys across a range of health services, in conjunction with the Department of Health and the HSE.

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Message from the Chief Inspector of Social Services

Mary Dunnion
Chief Inspector of Social Services and Director of Regulation

This report provides an overview of the first five years of regulation of designated residential centres for adults and children with disabilities in Ireland. It provides insight into the quality and safety of these services, and how the quality and safety of services has improved from 1 November 2013 to 31 October 2018. Importantly, it also reflects what residents have told us and what we have observed about their experience of living in these services.

The regulation of designated centres for people with disabilities is Government policy aimed at protecting the vulnerable people who live in these centres. When the State introduced regulation of this area in 2013, it set the minimum level of service a person can expect to receive. It provided, for the first time, a standardised approach for the assessment of quality and safety in all centres. When we started to regulate the sector, we found most services were doing a good job; others were severely challenged in providing a safe and high-quality service; and some were providing unsafe and substandard care.

During this time, we have seen a marked improvement in the services people receive. Our data on overall compliance with regulations across the past five years shows a gradual improvement year-on-year. Residents also regularly tell our inspectors about how these improvements have positively impacted their lives.

However, continued levels of non-compliance in relation to governance and management remain a cause for concern. Poor governance has a direct impact on the lived experiences of residents. Where a centre is poorly governed or managed, residents' care is adversely affected. This is a consistent finding across all service areas the Chief Inspector regulates. Providers need to continually strive to improve the quality of the life experienced by people who live in designated centres and provide safe services for them to live in.

Many residents continue to live in poorly maintained congregated settings, in buildings no longer fit for purpose, which must be addressed by providers as a matter of urgency.

Our inspections also show a consistent improvement in compliance every year with the regulations on promoting residents' rights. In our experience, this development has significantly improved the quality of life of people with disabilities, with many residents reporting that they viewed the designated centre as their home and loved living there. However, it is only in the last two years that there has been a significant shift in meeting residents' social care needs. Further work is required to ensure that all services are person centred and able to effectively meet the needs of residents on a continual basis.

While regulation has brought about increased awareness of the rights of people using these services, safeguarding issues continue to be regularly raised by our inspectors. In 2018, almost one in three centres failed to ensure that residents were adequately safeguarded in line with the regulations. Our inspectors will continue to focus on this critical area going into the future. We await the introduction of new *National Standards for Adult Safeguarding*, developed by HIQA and the Mental Health Commission, which are currently with the Minister for Health for his approval.

Throughout the past five years, we have used the powers in the Act proportionately and fairly in relation to the risks posed to the residents. In most centres, providers have responded by taking the necessary corrective action to address failings, and residents in these centres have steadily experienced improvements in their quality of life in safer, better governed centres. In other centres, we took regulatory action to ensure that residents were safe.

Residents' voices and opinions continue to be of the utmost importance to us. We have recently been meeting with residents' groups across the country to hear their views on how we regulate, and have introduced a new inspection programme to support and drive quality improvement in designated centres.

While challenges remain in the sector, HIQA continues to advocate for the rights of vulnerable people to live full lives in their communities, living in well-run, modernised pleasant surroundings which are safe, fit for purpose and designed to meet the changing needs of residents as they grow older. We also recognise that the model of regulation may need to change to ensure residents' needs are met into the future, and that other vulnerable people can receive the same legal protection that regulation provides.

Finally, I want to take the opportunity to thank the residents, their families and the staff and providers of designated centres for their cooperation and engagement with our inspectors and the system of regulation over the past five years and their

ongoing commitment to improving quality and safety of services around the country.

Mary Dunnion

Chief Inspector of Social Services and Director of Regulation

Health Information and Quality Authority

Introduction

This report reflects on key aspects of the first five years of statutory regulation of designated residential centres for people with disabilities in Ireland, which are home to over 8,800 people in 1,183 residential centres. During this time, regulation has worked to improve the standard of care and support for people living in these centres and has drawn public attention to how these centres are being run.

Following significant public concern in the preceding years that the absence of an independent regulator for this type of social care[(1)] was putting vulnerable adults and children with disabilities at risk,[(1-4)] the State developed regulations for these services.

The Chief Inspector of Social Services within the Health Information and Quality Authority (HIQA)[‡] started to regulate these services on 1 November 2013. This was the first time that such services were subject to independent regulation.

At the commencement of regulation, each provider had three years in which to be registered by the Chief Inspector (from 1 November 2013 until 31 October 2016). It became evident to the Chief Inspector, over the course of this initial three years, that the sector was not yet ready for the regulation, and many of these centres would have not been ready to be registered by 31 October 2016.

Following a submission to the Department of Health by the Chief Inspector, the Act was amended to extend this time frame to 31 October 2018, thereby allowing providers up to five years in which to achieve their first period of registration.

While not without its challenges, regulation of this sector has been a catalyst for change. As evidenced in this report, regulation has dramatically improved the safety and the experience of care and support provided to thousands of people with disabilities who live in regulated designated centres in Ireland.

From November 2013 to the end of October 2018, over 3,800 inspections of designated centres for people with disabilities were carried out by the Chief Inspector. These inspections found that while most services were doing a good job, others were struggling to do so, and some were providing unsafe and substandard care.

During 2013 and 2014, providers were found to be non-compliant with the regulations inspected in 41% of inspections. By 31 October 2018, the level of overall non-compliance with the regulations (and its associated negative impact on residents) had dropped to 24%.

[‡] Referred to as the Chief Inspector throughout this report.

This report provides an overview of regulatory interactions and the profile of designated centres. It describes the experience of the people who use these services and the engagement of providers with the regulation process. It also describes some of the key challenges encountered during the first five years of regulation of designated centres for people with a disability.

Short case studies in this report will illustrate particular challenges faced by providers in different settings, examples of the regulatory interventions taken by the Chief Inspector to address these challenges, and how regulation has positively influenced improvements to the quality of life of people using those services.

This report also shows how regulation provides an assurance to service users, their families, Government departments and the general public that people are being cared for and supported in a way that maximises their independence, protects their safety and promotes their fundamental rights to live how they choose.

Chapter 1. The regulatory framework

What is regulation?

The framework for regulating designated centres for people with disabilities (including children) is set out on a legislative basis in the Health Act 2007 (as amended) (referred to in this report as the Act), underpinned by associated regulations and supported by nationally mandated standards.[‡]

This framework is an effective measure of the quality and safety of care provided to vulnerable people. The regulations set the minimum standard of safety, care and support that a provider must achieve, while the national standards challenge providers to continually review and improve their service to go beyond compliance with minimum regulations, and to routinely and regularly improve the quality of the services that they provide.

The Chief Inspector is responsible for the regulation of designated residential centres for children and adults with disabilities under the Act. The Act requires all such services to be registered by the Chief Inspector as 'designated centres'. These centres are then subject to requirements in the Act, regulations and national standards.

A period of registration lasts for three years, and each provider is required to apply to renew the registration of a designated centre six months before the end of each period of registration.

The lived experiences of people with disabilities (such as their privacy, dignity and wellbeing, along with opportunities for greater independence and autonomy over their own lives) and how providers focus on improving the safety and quality of life for residents are fundamental components of regulation by the Chief Inspector.

The inspection process

Inspection is an important aspect of regulation. It allows inspectors to observe the daily routine of residents in a centre, to hear from them about what it is like to live there, or to observe interactions between staff and residents, and judge how well the provider is managing and overseeing the care and support provided to residents.

[‡] The regulatory framework is as follows:

— Health Act 2007 (Care and Support of Residents in Designated Centres for Persons (Children and Adults) with Disabilities) Regulations 2013

— Health Act 2007 (Registration of Designated Centres for Persons (Children and Adults) with disabilities) Regulations 2013, as amended

— HIQA's *National Standards for Residential Services for Children and Adults with Disabilities* (2013).

Inspections aim to determine the impact on the lived experience of residents through the provider's compliance with the regulations. For this reason, inspections can be announced or unannounced. Announced inspections enable greater participation of residents and relatives in the inspection process by letting them know when inspectors will be present in the centre. An inspection may also be announced if the inspector requires a particular person to be available during the inspection. Unannounced inspections can happen at any time of the day or night on any day of the week.

In the first five years of regulation, inspectors carried out 3,829 inspections (57% announced and 43% unannounced). These inspections were scheduled according to a range of criteria, including the level of assessed regulatory risk in the centre; the inspection history of the centre; and in response to the receipt of information that providers submitted. Other criteria included unsolicited information submitted by residents, family members, staff and or the general public.

During inspections, evidence is gathered about the quality of the service, the experience of the residents living there and the overall effectiveness of the providers and their managers in meeting the requirements of the Act and the regulations.

The Chief Inspector has published an *Assessment judgment framework for designated centres for people with disabilities*[5] which provides a useful guide to providers on the evidence inspectors will seek during inspection in order to assess and make a judgment on the overall level of compliance with each regulation. Compliance with the regulations is the minimum standard used in order to determine the quality of life, safety and experience of residents in designated centres.

Following an inspection, an inspection report is produced. Inspection reports detail what was found on inspection, including areas of good practice and high-quality care, areas where improvements are required, and any areas of non-compliance with the regulations. Where non-compliance is identified, the provider is required to submit a detailed plan, setting out how they will take action to comply with the relevant regulations. Inspectors also seek assurances that measures to improve residents' wellbeing and safety are implemented promptly and effectively.

Where inspectors find that the non-compliances result in a very poor quality of life for residents or high-risk of harm to the residents living there, the Chief Inspector increases regulatory activity up to and including cancellation of the registration of some centres where providers were unable to come into compliance. Whenever enforcement action is taken, the Chief Inspector will always try to minimise disruption and anxiety for people living in designated centres. However, the powers in the Act are used fairly to ensure a safe and high-quality service is and continues to be provided in these designated centres.

Publication of inspection reports

While meeting the regulations and national standards has been sometimes challenging for providers, and for some residents and their families, regulation has provided a standardised benchmark to consider the quality of centres. Regulation has also increased the transparency of how services are run by providers through the publication of inspection reports, HIQA's annual report and the Chief Inspector's yearly overview reports.

Escalated and enforcement actions

For the vast majority of providers, the application of the regulatory framework and inspections and continual monitoring is all that is required to ensure that residents' quality of life and services are being delivered safely and to a high standard.

Where a provider has failed to come into compliance, or the provider has not demonstrated that they are a fit provider, or there is a significant risk to the rights, dignity, quality of life or safety of residents, the Chief Inspector has a range of actions and enforcement powers available, including:

- issuing the provider with a warning and time frame to come into compliance
- developing a regulatory plan for the provider at organisational level (rather than individual centre level) where the root cause is the poor oversight and governance of services
- placing conditions on a centre's registration
- cancellation of the centre's registration
- prosecution.

Cancelling the registration of a designated centre is the most significant power available to the Chief Inspector. The Chief Inspector cancels registration as a last resort. See Chapter 9 for more information.

Enforcement proceedings can be very disruptive and upsetting for people living in designated centres and their families, and is only exercised where all other options have been exhausted. As such, the Chief Inspector ensures that the provider is given clear information and feedback about what is required to improve the safety and quality of the service for residents, and the time frame in which this must be achieved.

Over the last five years, the Chief Inspector has initiated large-scale regulatory programmes across a number of designated centres operated by a single provider where there is evidence of poor quality and risks to the safety of residents.[6, 7] These regulatory programmes have required the provider to demonstrate a clear improvement trajectory and are subject to close and regular monitoring by the Chief Inspector.

Throughout these programmes, the provider is required to meet with the Chief Inspector on a regular basis and provide updates on its progress. In addition, more frequent inspections may take place in these centres in order to gather evidence and to monitor the provider's progress and the impact these improvements have had on the safety and quality of life for residents. Two examples of where such programmes of regulation have been used are in Stewarts Care Limited and Áras Attracta, with overview reports available at www.hiqa.ie.

Chapter 2. Profile of designated centre for people with disabilities in Ireland

Introduction

A designated centre for people with a disability is defined in section 2(1)(a) of the Health Act 2007. Designated centres may be comprised of a number of buildings clustered together as a large campus, a campus made up of a number of individual designated centres, or individual designated centres located in the community. In Ireland such centres are home to over 8,800 people with disabilities.

The number of designated centres for people with disabilities across the country continues to increase every year. These centres can be registered to accommodate adults, children, or a mix of adults and children.

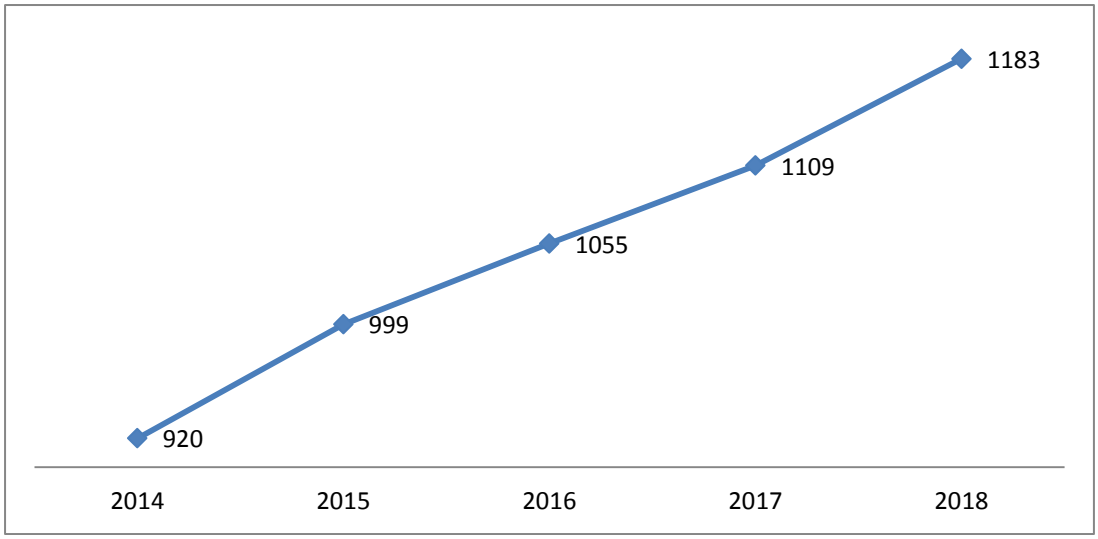
In Ireland, all residential centres for people with disabilities are State funded. These include centres which are operated directly by the State through the Health Service Executive (HSE), by voluntary and non-governmental organisations, or by private entities which are funded by the HSE. However, in recent times, there has been growing demand for additional funding for disability services.[8, 9]

Number of designated centres

When the regulations commenced in 2013, all organisations that had been operating residential services for people with disabilities up to that time, and that met the legal definition of a designated centre, were required to notify the Chief Inspector that they were operating as such. In November 2013, a total of 920 centres were declared as operating in the sector, providing residential placements for approximately 8,000 people.

The Chief Inspector's data,[10-14] spanning the first five years of regulation of residential centres for people with disabilities, shows a sustained increase in the number of such designated centres year-on-year. Between 2014 and 2018 an additional 263 centres were registered, representing an overall increase of 28.5% in the number of designated centres during that time. By 31 October 2018, 1,183 centres were registered by the Chief Inspector.

Figure 1. Increase in the number of designated centres for people with disabilities in Ireland*



*also referenced in HIQA annual reports 2014–2018.

One reason for this increase is the continued drive within the sector to reduce and ultimately close all large congregated settings (large institutions), in line with the HSE's national policy, *Time to Move on from Congregated Settings: A Strategy for Community Inclusion* policy in 2011.[15]

The HSE defines congregated settings as follows:

> Congregated settings are where 10 or more people with a disability live together in a single living unit or are placed in accommodation that is campus based. In most cases, people are grouped together and often live isolated lives away from the community, family and friends. Many experience institutional living conditions where they lack basic privacy and dignity.[15]

Other reasons for growth in the number of designated residential centres include a provider responding to overcrowding, or to alleviate the impact of residents with differing care and support needs living together in existing centres, or to emergency accommodation needs arising for people with disabilities. Demand for residential places in designated centres for people with disabilities in the State is expected to continue to grow over the coming years.[16] For example, in its 2017 annual report, the Health Research Board highlights that an additional 2,179 full-time, residential placements will be required between 2018 and 2022, in order to meet the future needs of people with disabilities.

Number of residential places in each centre

Providing an appropriate place for residents to live is a fundamental part of meeting the needs of people living in residential centres. Factors which impact negatively on the wellbeing, safety, health and quality of life of residents include:

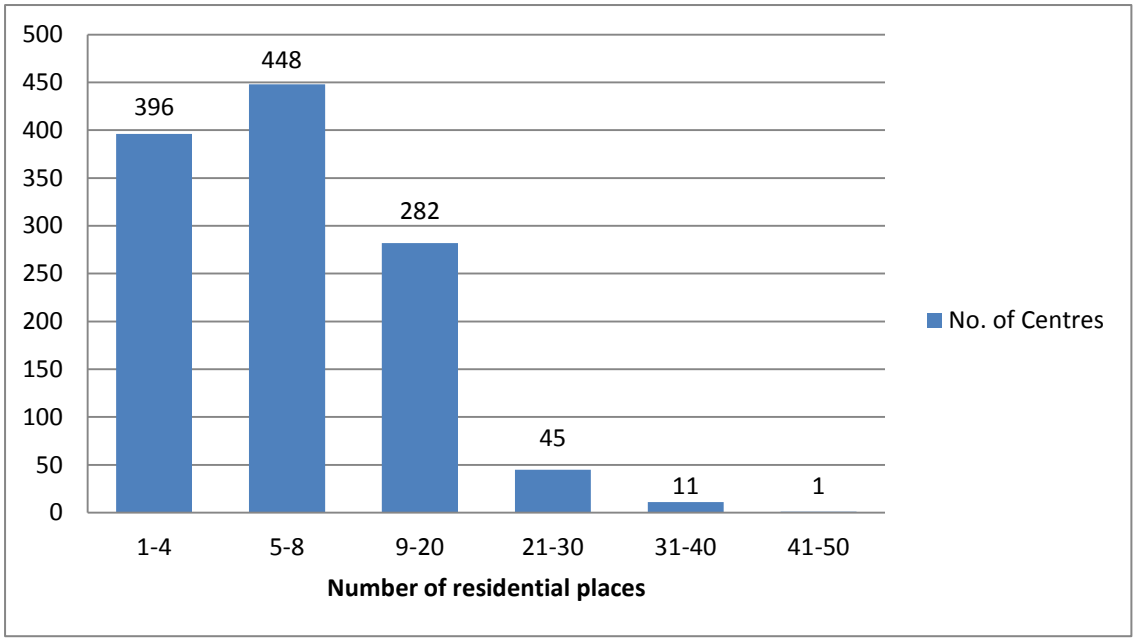
- the design and layout of the designated centre not meeting the assessed needs of residents
- overcrowding, or
- where residents who have widely different needs have no choice but to live together in the same shared bedroom or centre.

It is difficult to provide an accurate figure for the number of people living in designated centres, particularly in the early years of regulation. For the five-year period beginning in late 2013, the Chief Inspector progressed with a programme of registration and could only accurately state the number of people living in centres that had been formally registered.

By 31 October 2018, there were 8,894 residential places in designated centres for adults and children with disabilities. There were 8,287 places for adults, 320 for children and a further 287 placements for either adults or children. In 2018, the average number of residents living in each centre was just over seven people (7.66). In the largest designated centre, 43 people lived together and one person lived in the smallest centres.

Figure 2 shows the breakdown of centres according to the number of registered residential places in the centre. These figures only include people living in residential units that meet the definition of a designated centre. Research published by HIQA in 2017 showed that there was a large number of people with disabilities living in other kinds of residential services which do not fall under the definition of a designated centre in the Act — despite service users in these unregulated sectors being potentially just as vulnerable as those living in designated centres.[17, 18] It is anticipated that the range of care and support services presently outside the definition of a designated centre will in the future, through the introduction of homecare regulation and safeguarding legislation, provide these people with the same protections.

Figure 2. Number of registered residential places in designated centres for people with disabilities in 2018



Designated centres and residential places by type of service

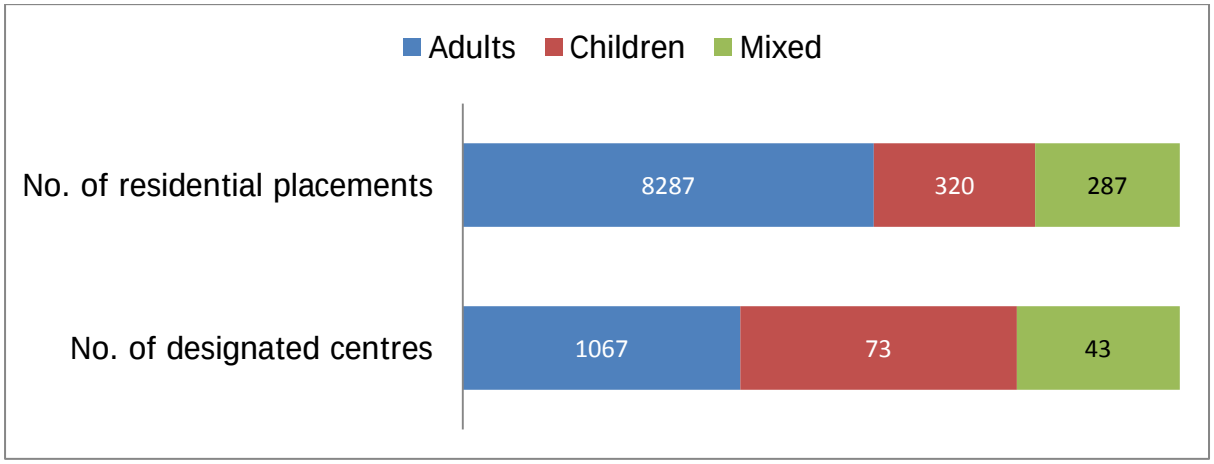
Registered providers can apply to register three types of designated centre for people with disabilities:

- adult centres
- children's centres
- and mixed centres (adults and children).

Most people with a disability living in designated centres in Ireland are adults. More than nine out of 10 residential places are in services exclusively for adults (93.2%), while 3.6% of places are for children. The remaining 3.2% of residential places are in centres where both adults and children live together, primarily in respite settings or where some children in the centre have now reached adulthood.

In some of these centres, the provider has decided to continue to provide a service to all residents whenever children reach adulthood, and change the service to provide care and support to adults only. The number of centres and registered placements in each type of centre is shown in Figure 3.

Figure 3. Designated centres and residential placements by type of service



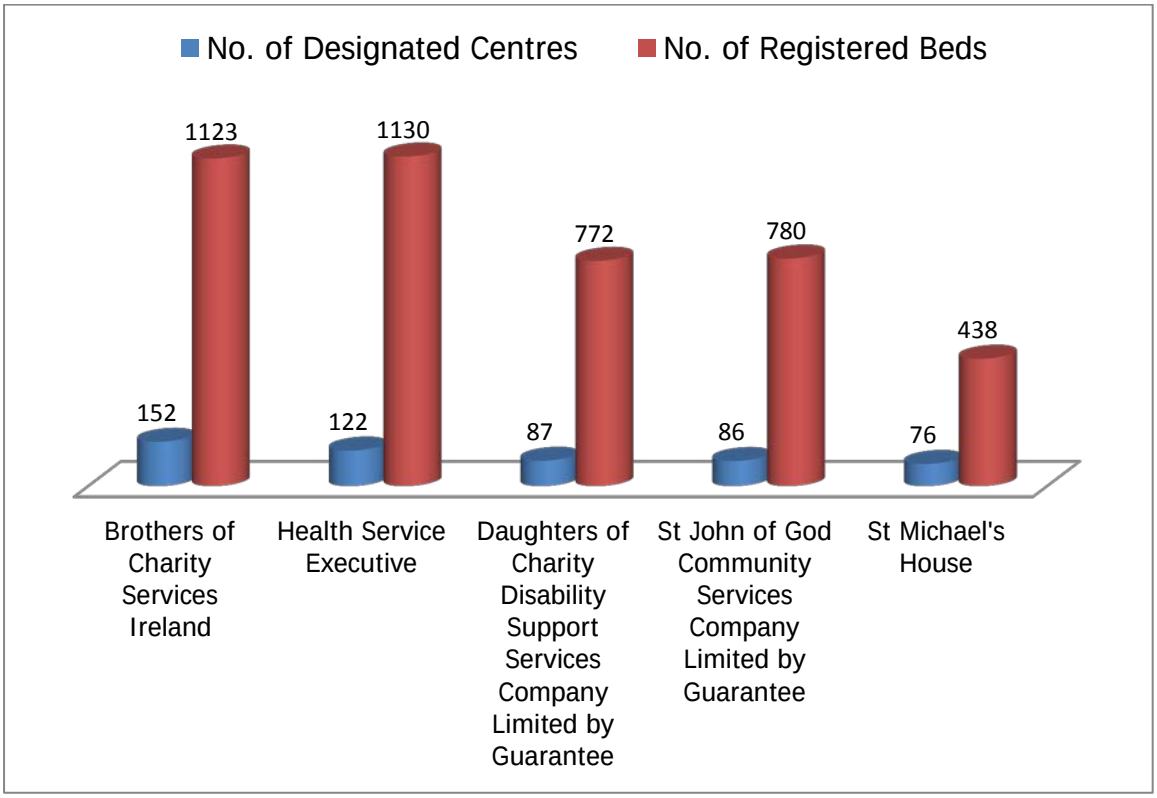
Registered providers

By October 2018 the total number of residential places in designated centres for people with disabilities stood at 8,894, with 82 registered providers operating residential centres for adults and children with disabilities across the country. Five of these providers account for almost half (47.7%) of all registered residential placements in the country.

The provider with the largest number of centres was the Brothers of Charity Services Ireland (a voluntary organisation) with 152 centres and 1,123 registered beds. The HSE is the largest provider of services in terms of residential places (with 1,130 registered places). By October 2018, the HSE directly operated 122 designated centres for people with disabilities, including eight centres which it took over from other providers following the Chief Inspector cancelling the centres' registration.

See Figure 4 for information on the five largest registered providers of designated centres for people with disabilities in Ireland.

Figure 4. Five largest providers of residential disability services in 2018



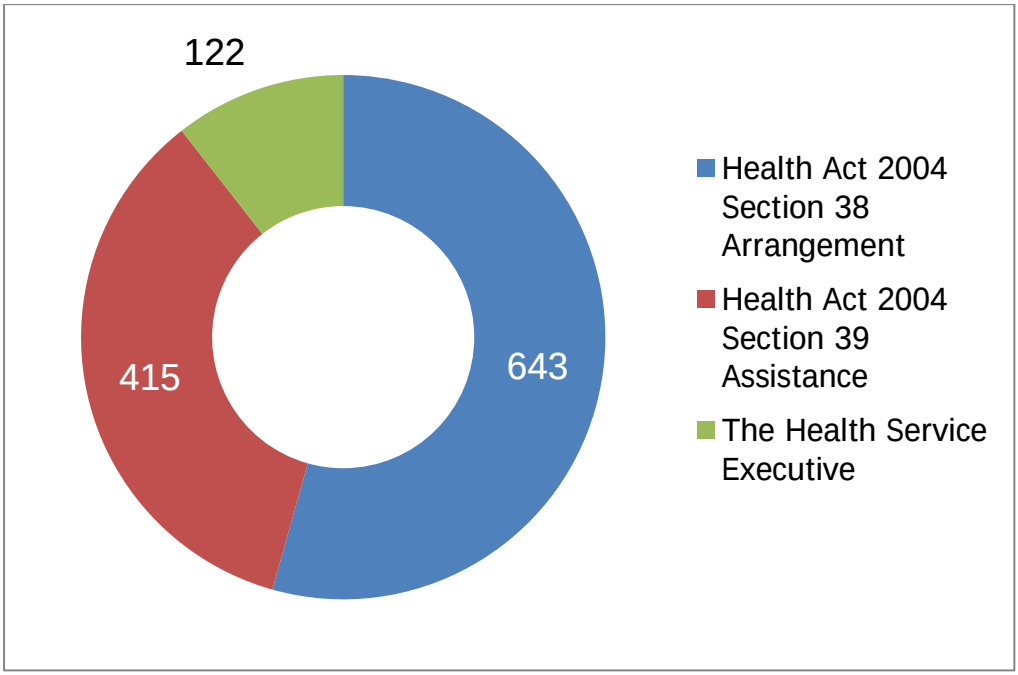
Funding arrangements

All designated centres for people with disabilities in Ireland, whether statutory, voluntary or private, receive funding from the State to operate the service.

Private and voluntary registered providers receive funding from the HSE through what are commonly referred to as 'section 38 arrangements' or 'section 39 assistance'. This is a reference to sections 38 and 39 of the Health Act 2004 which allows the HSE to fund organisations to provide services on its behalf.[19]

Figure 5 shows the breakdown of centres by funding type in 2018. **Case study 2 — regulating for improvement** looks at the adequacy of funding in one particular service and the steps taken by the Chief Inspector in response to concerns about the centre's financial viability.

Figure 5. Breakdown of centres by funding type



Chapter 3. Impact of regulation on residents' lives

Introduction

The commencement of regulation in November 2013 resulted in the development of an independent standardised assessment of the quality and safety of services in designated centres for people with disabilities for the first time.

Over the past five years, findings from our inspections have consistently highlighted three principle characteristics that determine a good service.

1. A staff culture that promotes and protects the rights and dignity of residents through person-centred care and support.
2. A service that is led by a capable person in charge (supported by the provider) who is knowledgeable about the support needs of residents. This is demonstrated through high-quality safe care and support.
3. A provider who has robust arrangements in place to assure itself that a safe, good quality service is being provided to residents. This is demonstrated through good governance and management.

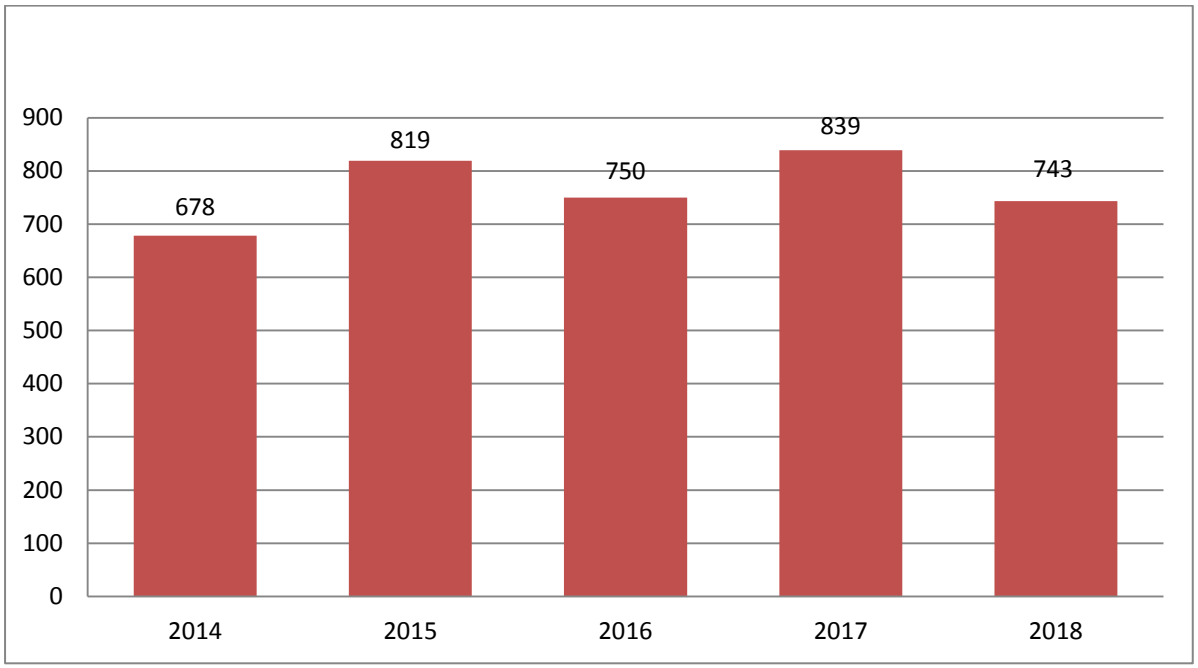
This chapter gives an overview of how these principle characteristics impact on the lived experiences of people who use these services.

How we judge compliance

Inspection is a fundamental component of the assessment of compliance with regulations and national standards. More frequent inspections are carried out in centres with high levels of repeated non-compliance with the regulations and standards.

Within the first five years of regulation, the Chief Inspector carried out 3,829 inspections of designated centres for adults and children with disabilities (see Figure 6 for a breakdown for each year). Of these, 57% were announced and 43% were unannounced.

Figure 6. Number of inspections of designated centres for people with disabilities, November 2013 to October 2018



Note: 2014 includes November and December 2013; 2018 represents data up to the end of October 2018.

Engaging with residents during inspections

Residents' voices, views and experiences are crucial in determining how a service is performing. Listening to residents and gathering evidence on their experience of life in the centre are therefore crucial parts of HIQA's inspection process.

Although some residents may not be able to communicate with inspectors due to the nature of their disability, or may choose not to engage, inspectors make every effort to engage with residents during inspections. This will either be through communicating directly with residents, communicating with residents through an advocate or family member or member of staff, meeting groups of residents or through gathering written feedback using questionnaires to seek their views on different aspects of day-to-day life in the centre.

HIQA is very aware that a designated centre is a person's home and that inspections may be considered an invasion of one's privacy and a disruption for people living in designated centres. Inspectors are mindful of the concerns of residents and take measures to address those concerns wherever possible, including minimising disruption to the residents' and staff members' normal routine.

Unannounced inspections are a feature of how services are inspected and are necessary to ensure inspectors get an accurate picture of normal, daily life in a centre. However, they can be a source of anxiety for the people who live there. Where inspections are announced, the inspector will ask the registered provider to

tell us about any specific needs that residents may have in advance of the inspection. In some cases, this may involve meeting with a resident in a different location so that they can meet the inspector in person prior to the inspection.

Posters are sent to centres prior to inspection with details of the upcoming announced inspection. Providers are asked to display these prominently in the centre in order to tell residents, relatives, visitors and staff about the inspection and to invite them to meet with inspectors during the inspection if they wish to do so.

Questionnaires which ask residents about their experiences of the service are sent out to centres in advance of inspections. This allows residents and relatives to give their feedback. Following feedback from family members and residents, HIQA revised the questionnaire for residents in 2017. The questionnaire is also available to download on www.hiqa.ie and can be completed by residents or carers outside of the inspection process and sent directly to us.

Engaging with residents outside of inspections

The Chief Inspector accepts information or feedback about residents' experiences of living in a designated centre, or with the inspection process, at all times.

Over the first five years of regulation of designated residential services for people with disabilities, the Chief Inspector has taken a number of steps to engage proactively with residents and national advocacy bodies. This has been done primarily through meetings with local and regional residents' groups.

In 2018, inspectors attended six resident group or advocacy meetings across the country to listen to residents talk about their experience of inspections. Inspectors asked residents about their experience of regulation and how this has impacted on their quality of life and lived experience.

HIQA continues to build on this approach into the future and inspectors plan to meet groups of residents around the country to listen to their experiences and use their views to further promote quality improvements in the residential disability sector.

How to capture the resident voice

Inspection reports have undergone a number of changes since the beginning of regulation in 2013. One criticism of the inspection reports in the early stages of regulation was that they did not adequately reflect the voices of residents. A review of the first 50 inspection reports by Inclusion Ireland concluded that "...the voices or words of the resident with a disability were faint or absent entirely from reporting".[(20)]

Revised inspection reports now include a section titled, 'What residents told us and what inspectors observed'. In this section, inspectors outline what residents told them on the day of inspection about what it is like to live in their home. As some people are not in a position to communicate verbally with inspectors, observation is used to describe the interactions between staff and residents, the environment and the general atmosphere in the centre.

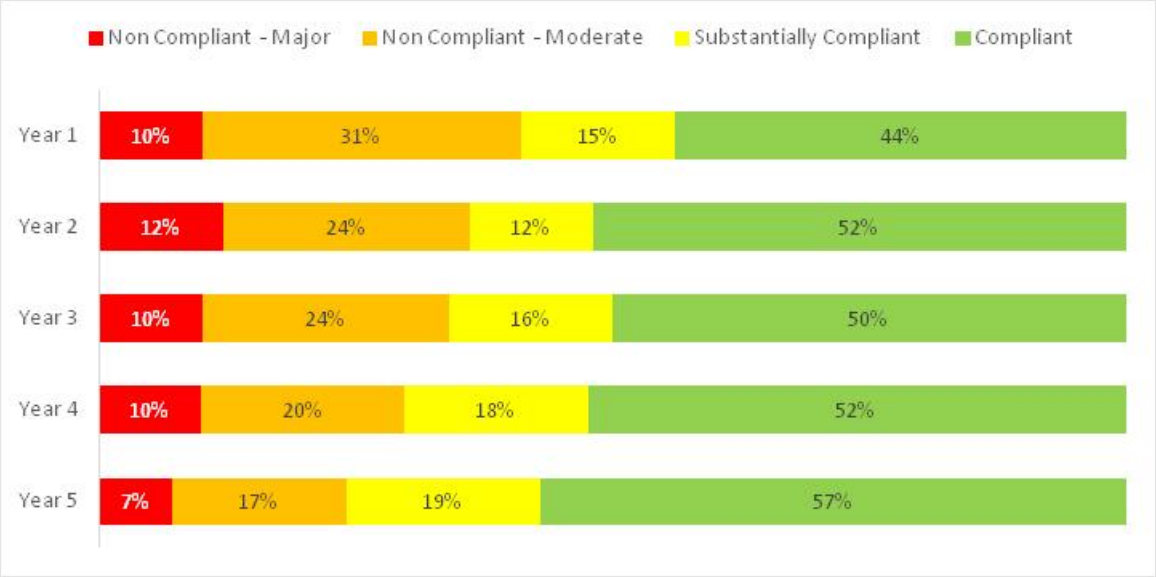
The impact of compliance with regulations on residents' experiences

Where providers have taken action to meet the requirement of the regulations, there is evidence of positive outcomes for residents — this means that they are living in safe environments, free from the risk of harm and are able to enjoy meaningful lives, of their choosing, in their local communities. Where a provider fails to meet the minimum requirements of the regulations, this will have a direct impact on the lives of residents and may increase the risks of negative outcomes on their quality of life or their safety.

Inspection data shows that compliance with most regulations has improved over the first five years of regulation. Figure 7 compares the level of overall compliance with the regulations in the first year of regulation with the level of compliance found in 2018.

This data is a composite overview of all of the areas in a centre assessed by inspectors in a particular year, broken down by those findings that were compliant or substantially compliant with the regulations versus those that were not compliant. A description of these judgments can be found in Appendix 1.

Figure 7. Comparison of compliance with all regulations assessed, November 2013 to October 2018



Note: Year 1 includes November and December 2013 and all 2014; Year 5 is to the end of October 2018.

This high-level overview of compliance in centres demonstrates that at the commencement of regulation in the sector — in 678 inspections completed in Year 1 — 59% of those inspections providers were either in compliance or substantial compliance with the regulations, while improvement was required in 41% of those inspections with 10% found to be in major non-compliance with the regulations. In comparison, by 2018, a significant shift towards compliance was found, with 76% of the regulations inspected (during the 743 inspections) either in compliance or substantial compliance with the regulations.

However, as almost one in four regulations remain not compliant (24%), further improvement is required across the sector in order to ensure that all residents are receiving good quality and safe services. Throughout the following chapter, the experience of residents are used across key areas of the regulations, which impact most significantly on their lives, to illustrate the effect regulation of the sector has had on improving the overall quality of their lives, and the safety of services.

Chapter 4. Promoting residents' rights and consulting with them

Introduction

In order to protect and promote the rights of people with disabilities living in residential services, it is imperative that there are systems in place to ensure they participate in, are consulted with and consent (with support if required) to make decisions about their own lives.

The regulations relating to residents' rights and respecting self-determination are an important indicator that describes to what degree a service is person centred. These focus on how residents should be consulted with about the care and support that they receive and about how their centre is being run. It also includes how residents have their privacy protected and dignity upheld. Supporting autonomy and personal control is a pronounced goal in a person-centred planning process.[(21)]

Findings from inspections

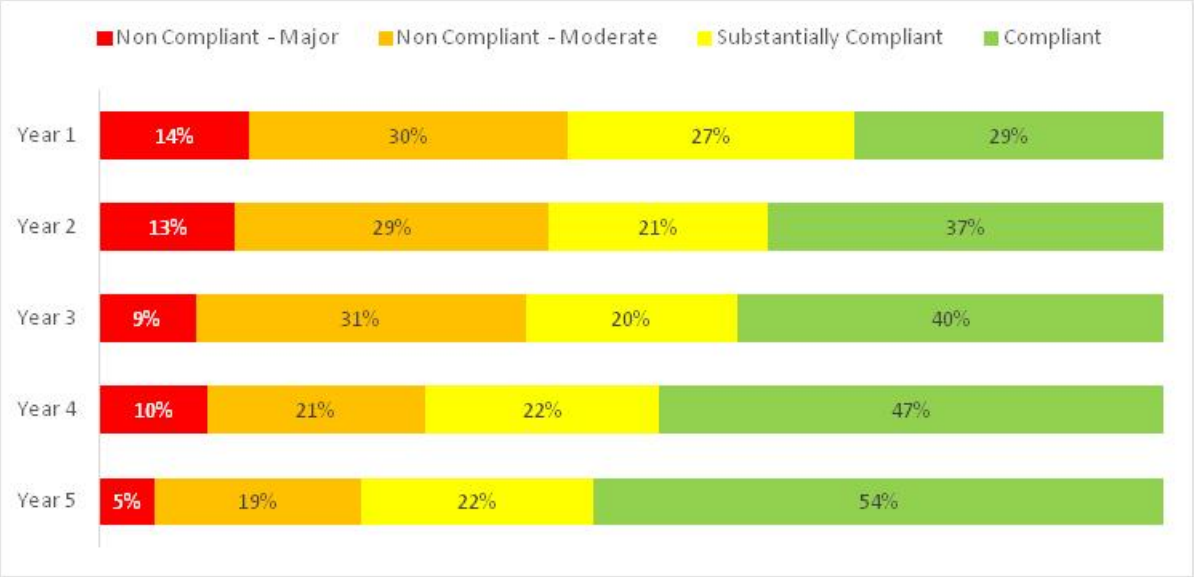
Initial inspections carried out by the Chief Inspector from 2013 to 2015 found that some people living in residential care were not being consulted appropriately nor had their rights promoted. Of all regulations relating to residents' rights and consultation inspected in Year 1, 44% were found to be not compliant.

Some residents told inspectors that they were not consulted with about how the centre was run, were not informed about staff rosters and did not know from one day to the next who might be supporting them. This lack of consultation had a negative impact on their quality of life and at times they felt vulnerable and concerned when not kept informed. One inspection found the following:

> "While the resident appeared comfortable in their new home, they indicated to the inspector that they did not know who was on duty that night, or tomorrow and appeared somewhat anxious about this, listing names and asking the inspector who would be on duty."

The first five years of regulation led to a consistent improvement year-on-year in compliance with the regulations on promoting residents' rights. Figure 8 demonstrates the impact of regulation over that time. By Year 5, on average, people living in residential disability services had experienced a gradual and sustained improvement in how they were consulted with and how their rights and dignity were promoted and upheld.

Figure 8. Five-year findings on compliance with the regulation on residents' rights, November 2013 to October 2018



Note: Year 1 includes November and December 2013 and all 2014; Year 5 is to the end of October 2018.

Inspections carried out in 2017 and 2018 found a marked improvement in how residents' rights were being respected and promoted. Many residents told inspectors that they were now consulted with about all aspects of their care, and staff rosters were now available to them (in some instances in a visual format to suit their communication preference and style) — they now knew who would be supporting them each day.

While a number of services and providers were still not adequately ensuring that the rights of residents were being upheld and promoted by Year 5, nationally, services are heading in the right direction. This shift has significantly improved the quality of life of people with disabilities, with many residents reporting that they viewed the designated centre as their home and loved living there, such as in this report:

> "Residents loved their homes and were very happy and content with the staff who supported them. Some residents had transitioned out of larger settings to these community houses and were very positive and happy with their moves. Residents told the inspector they would never move back and would not change anything with their service."

They also made their own decisions concerning the day-to-day operational management of their home. For example, they were involved in planning menus, deciding for themselves what social activities to engage in, what day services to attend and where to go on holidays. An inspection carried out in 2018 reported:

> "Throughout the inspection residents were observed to participate in the daily running of their homes. Residents were consulted about decisions and their preferences and requests were accommodated."

Later inspections also found that, for many residents, a change in their living environment had enhanced their right to a better quality of life, in relation to their right to choice, privacy and dignity.

For example, some residents (for the first time in their lives) chose to have their own bedrooms and, in some cases, could pick their own curtains, duvet covers and furniture, which provided for their own private and intimate space. It is important for people with disabilities to have a quiet space to which they can choose to retreat (especially if they become anxious or concerned about an issue) and for many, this might be their own individual bedroom.[(22)]

Other residents chose to engage in life skills development programmes, where their right to choice and autonomy was supported. This resulted in better opportunities to access to their community. For some, new life experiences, such as securing a job, were supported. These lessened people's dependency on the service and promoted their independence. For example, an inspection report from 2018 noted:

> "The resident described and the practice observed reflected how their rights, privacy, choices and independence were promoted; for example the resident spoke with pride of having secured employment."

Inspectors found real improvements in the quality of life of residents who were supported to follow their goals and wishes. Notwithstanding this progressive improvement, the data also shows that in a significant number of services, one in four, providers are still not adequately upholding or promoting the rights of residents.

Case study 1 shows where this key objective was being attained and where it was not.

Case study 1 — Promoting the rights and dignity of residents through regulation

High levels of non-compliance identified

This centre is based in a rural location and is described as a campus-based or congregated setting made up of a number of designated centres. All inspection reports in relation to this case study have been published by the Chief Inspector. The first inspections were carried out between 2015 and early 2017 and found high levels of non-compliance with the regulations. Inspectors found that the premises were not fit for purpose and were significantly and negatively impacting on the rights, privacy and dignity of residents. For example, in one area, there were dormitory-style bedrooms where residents had little or no privacy and where the behaviours of some residents, which were upsetting to other residents, were being inadequately managed. In another area on the campus, inspectors found:

> "...the dignity of residents was significantly compromised. Control measures had been implemented by staff to reduce the impact that the layout of the premises had on the privacy and dignity of residents. However the implementations of the control measures were not consistent throughout the centre. For example, the bathrooms were directly accessed from the communal areas. In some instances staff ensured that the door to the bathroom was closed at all times, whilst in other areas the door remained open at all times. Therefore occupants of the communal area were aware of all activities being undertaken in the bathroom".
>
> (Report of inspection which took place in March 2015)

Inspections also found that residents were not consulted about the running of their home and significant compatibility issues between some residents resulted in safeguarding concerns that were not being managed appropriately. For example, an inspection in January 2017 found that:

> "...some residents had no choice but to leave their home for up to 12 hours every day as it was not safe for them to be there. These residents were subject to incidents of aggression and violence from other residents and the centre was managing this by keeping the residents out of their home for prolonged periods of time. Because of this issue it was also observed that these particular residents' intimate care needs could not be supported in their own home and they had no alternative but to use a different facility (everyday) for showering and bathing."
>
> (Report of inspection which took place in January 2017)

Regulator takes action

As a result of these findings over a sustained period of time, the Chief Inspector took enforcement action to ensure that the provider took adequate and appropriate action to improve the quality and safety of these services and the quality of life of people living there. By February 2017, notices of proposal to cancel the registration of two of the designated centres had been issued. The Chief Inspector also required the provider to develop and implement a specific service improvement plan. The provider had to submit monthly progress updates on improving residents' quality of life and in implementing stronger governance and oversight on the campus.

Impact of regulation

By mid-to-late 2017 onwards, inspections on the campus found that the quality and safety of care being provided to residents had improved significantly as a result of the regulatory intervention made by the Chief Inspector. Inspectors found that:

- community-based activities had increased for residents
- the provider had taken actions to ensure the safety of residents
- the number of harmful incidents involving residents had greatly reduced and
- access to external, independent advocacy for residents had been sourced.

While some issues relating to the premises remained, inspectors found that these issues were being managed better and that overall many improvements had been made to both the premises and the overall quality of residents' care and support. The improvements were such that the Chief Inspector did not proceed to cancel the registration of these centres.

A number of residents had also moved out of the campus to smaller individualised community-based homes during 2017 and 2018. This significantly reduced the risks associated with compatibility issues between some residents and promoted a safer living environment for those who continued to live on the campus. The ongoing de-congregation of this campus also meant that multiple-occupancy bedrooms were no longer required, further promoting the dignity and privacy of the remaining residents.

Inspectors found very positive outcomes for residents who had moved to community-based homes in late 2017 and early 2018. For example, an inspection carried out in 2018 found that:

"...residents were becoming involved in their local community since transitioning to their new home. One resident had transitioned to the centre from a campus based setting and was now starting to integrate into the local community. For example they were now able to walk to local amenities. Both residents were sports fans and the local football club was located across the road from their new home. They were both planning to attend a match there on the evening of the inspection".

(Report of inspection which took place in April 2018)

This inspection also found that residents were now more involved in the running of their centre. They were consulted on food menus and were involved in planning their individual and social activities. Visual communication tools had been developed to facilitate this consultation. Most importantly, residents themselves had indicated that they were happy living in their new home:

"...one resident was being supported to have their own key to their home. A specific kettle had also been purchased to facilitate residents to make their own tea and coffee when they wished."

(Report of inspection which took place in April 2018)

Chapter 5. Keeping residents safe from abuse

Introduction

At the time of writing, there is no specific safeguarding legislation in place in Ireland to provide a legal basis for the protection of vulnerable adults outside of the criminal justice system. However, the regulations[(23)] place a duty of care on providers to ensure that residents of designated centres for people with disabilities are kept safe from all forms of abuse.

In the wake of the disturbing and abusive practices experienced by some people living in Áras Attracta in Co. Mayo,[(24)] the HSE (the registered provider of this centre) developed a national safeguarding policy. This policy is, however, limited to HSE centres or centres funded by the HSE and has not been placed on a statutory footing.

The Government has also made positive steps, such as developing the Adult Safeguarding Bill 2017; however, in the absence of legislation or national policies, HIQA and the Mental Health Commission (MHC) have jointly developed *National standards for adult safeguarding*, which are currently with the Minister for Health awaiting approval.

HIQA looks forward to the Minister approving this key piece of work, and hopes to see the standards adopted across health, social care and mental health services soon. National and international evidence consulted as part of the development of these standards was published by HIQA and the MHC in 2018 (*Background document to support the development of national standards for adult safeguarding*), and is available on the HIQA website.[◇]

Common factors impacting on safety and safeguarding

There are many factors which may negatively impact on the safety and safeguarding of residents living in a designated centre, including the incompatibility of the residents living together, that is to say, the inability of residents to live together harmoniously. For example, some residents may not be able to tolerate noise created by other residents or if they have no private room of their own, find it difficult to cope with their private space being encroached upon by others. This may result in verbal and or physical aggression between residents due to their incompatible living arrangements, and it requires staff to be vigilant at all times to ensure residents facing these situations are kept safe.

[◇] Health Information and Quality Authority (HIQA) and the Mental Health Commission (MHC). *Background document to support the development of national standards for adult safeguarding*. Dublin: MCH and HIQA; 2018. Available online from: https://www.hiqa.ie/reports-and-publications/standard/background-document-support-development-national-standards-adult.

Poor or inappropriate living environments for people with disabilities can also create safeguarding issues in services. For example, residents presenting with behaviour that challenges can create complex safeguarding issues. Behaviour that challenges are known to increase in institutional settings or impoverished environments where typically there is a lack of engagement, poor social support and higher rates of restrictive practices.[25] Indeed, behaviour that challenges has serious implications for people with learning disabilities, such as social exclusion, deprivation, physical harm, abuse and exposure to ineffective or aversive interventions.[26]

Reporting obligations in relation to abuse

Providers are required to submit statutory notifications to the Chief Inspector of any allegation, suspected or confirmed, of abuse of any resident living in the centre. In addition, they are also required to investigate these allegations and take action to protect residents from abuse or harm at all times. Inspectors review these notifications and may follow up with the provider or carry out an inspection where required.

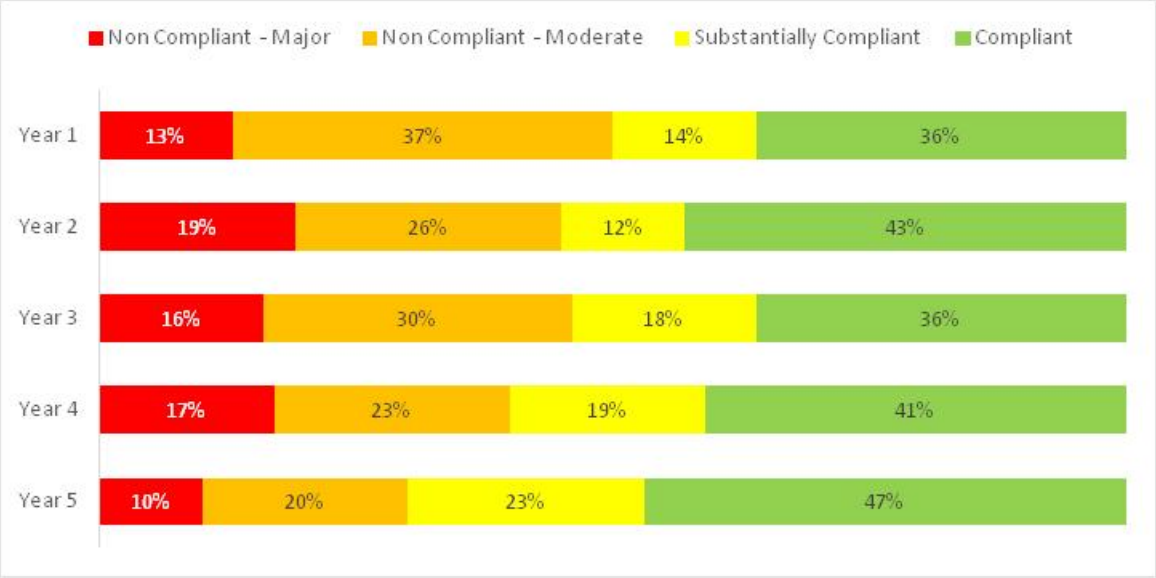
In addition, inspectors review key records during inspection, such as the provider's incident reports and residents' care and support records. This identifies if all incidents of suspected or confirmed abuse have been reported appropriately, including where necessary to the HSE's Safeguarding Office, An Garda Síochána (police) or other agencies, such as the Child and Family Agency (Tusla).

Where a provider has failed to notify the appropriate agency of safeguarding issues within its service, the Chief Inspector notifies these agencies independently.

Findings from inspections

As demonstrated in Figure 9, the first year of regulation found that significant improvement in the area of safeguarding was required in the centres inspected, and while some improvement was noted in the second year of regulation, this trajectory was not sustained into Year 3.

Figure 9. Findings on compliance with measures to keep residents safe, from November 2013 to October 2018



Note: Year 1 includes November and December 2013 and all 2014; Year 5 is to the end of October 2018.

While improvements in safeguarding were made in Year 4 and Year 5 of regulation, almost one in three centres inspected failed to ensure that residents were adequately safeguarded at all times in 2018.

Other safeguarding issues may arise wherever there is poor understanding and an inadequate response to residents' assessed needs. They may also arise where there is a lack of adherence to local and national safeguarding policies, and where there are poor governance arrangements and managerial oversight in the designated centre.

Where inspections found residents to be at immediate risk of harm, the Chief Inspector has required providers to take immediate action to improve the safety of their services. Where providers have failed to demonstrate they have the capacity or capability to provide a safe service, these centres have been subject to increased regulatory activity, and where necessary, have been issued with notices of proposal to cancel their registration (see **case study 2** in this chapter).

The evidence gathered through inspection during the first five years of regulation demonstrates that there remains a need for further improvement in the safeguarding and safety for all people with disabilities living in designated centres in Ireland. Safeguarding legislation would be a welcome addition to protect residents from all forms of harm.

In addition, in conjunction with Safeguarding Ireland, HIQA has produced draft *Guidance on a Human Rights-Based Approach to Care and Support in Health and*

Social Care Settings. This guidance provides additional support to people working in adult health and social care settings in understanding a human rights-based approach and implementing national standards. A public consultation on this guidance has ended and HIQA hopes to publish it later this year.

Case study 2 — Regulating for improvement

This centre is a small community home for up to seven adults with disabilities. All related inspection reports have been published by the Chief Inspector. The provider was originally formed as a family response to the lack of suitable services for children with a disability in their local area. Initially, the provider supported children with disabilities through a school for children with special needs, but as the children grew up, this centre was established to provide both respite and residential support.

During an inspection in 2015, the inspector found a good quality and safe service was being provided to residents, but improvements were required in relation to fire safety, risk management and to some operational policies. Residents also told the inspector of the positive elements of living in the centre:

> "...'[I] enjoy [my] trips to see family and [I am] able to have regular short breaks and do [my] shopping when away'... staff had time to spend with them individually and time to take them out...[we do] not have to wait an excessive time for assistance with personal care or to access a staff member on any occasion... [we feel] safe and well cared for by staff and could talk to staff at any time... if they had a complaint they would feel confident that they could approach staff and that their concern would be addressed".
>
> (Report of inspection which took place in June 2015)

However, an inspection in April 2016, following an application by the provider to register this centre, found that although residents were still supported to access a range of activities in the community, the governance and management of the centre had significantly deteriorated. For example, the inspector found that residents were at risk of harm due to poorly managed safeguarding processes:

> "...protective measures had not been put in place to safeguard residents to ensure they felt safe... there were inadequate local procedures to guide staff in the event of an allegation of abuse... allegations had not been investigated in line with the organisational or national policy and safeguarding procedures."
>
> (Report of inspection which took place in April 2016)

In addition, the inspector found that the provider had extended the service from a five-day to a seven-day service without adequate preparations; this led to a high reliance on agency staff to run the service. During a review of staffing arrangements in the centre, the inspector was advised of serious concerns relating to the financial viability of the service:

> "The inspector was told by the provider nominee[‡] that that there were financial issues in this centre... the current funding for staffing the centre was inadequate and prior to Christmas 2015 there were [an] insufficient number of staff working in the centre... a review of the financial viability of this service carried out by the inspector and validated by the provider nominee demonstrated that the centre was not sufficiently resourced to maintain services at the level currently being provided."
>
> (Report of inspection which took place in April 2016)

Regulator takes action

The inspector concluded that the provider had failed to adequately oversee and manage this service and that this was having a direct negative impact on the quality of life and safety of the residents living in this centre. The response of the provider to the issues identified on inspection was inadequate, and the provider attended a warning provider meeting[^] with the Chief Inspector. The provider was required to submit a time-bound improvement plan to the Chief Inspector, to address:

- the capacity of the management team and board to manage the centre
- the provider's plans to ensure good management of the centre
- confirmation of the centre's ongoing financial viability, and
- an updated action plan response to the April 2016 inspection setting out how the provider was going to improve:
    - the safeguarding arrangements and
    - other areas impacting on negatively on residents.

Impact of regulation

[‡] A provider nominee was a person who was nominated to speak to the Chief Inspector on behalf of the provider. More recently this role has been replaced with the 'registered provider's representative'.
[^] This is a meeting between the relevant case-holding inspector; Deputy Chief Inspector and or regional manager; and a provider. This meeting has a number of purposes, including communicating the risk to the provider and the required actions to be taken, and to issue a formal warning letter to the provider.

Following on from this meeting, an inspection in December 2016 found that the provider had made significant improvements in the governance and management arrangements in the centre. The provider had secured additional funding for the service and was now able to demonstrate its financial viability. Improvements had also been made to the quality of safeguarding arrangements in the centre, which had resulted in a reduction of peer-to-peer incidents where residents were causing harm to other residents.

During this inspection, residents reported that they now felt safer in the centre. This was in part achieved by the provider reducing the maximum occupancy in the centre from seven residents to six. Given these tangible improvements, and the actions taken by the provider to alleviate the risk of safeguarding concerns, the Chief Inspector registered the centre with a maximum occupancy of six residents.

An inspection in March 2018 found that the provider had continued to improve the quality of the service. Residents met with the inspector and told them of all the interesting things that they were doing on a regular basis, including participating in activities in the community. Residents were very complimentary of the staff working in the centre and they reported that staff were actively supporting them to plan and achieve their goals. Residents were also complimentary in terms of the management of complaints in the centre:

> “Residents were aware of the provider's complaints procedure and told the inspector that they had made complaints when they were unhappy about the service they received. The residents told the inspector that staff had listened to them and addressed their concerns.”
>
> (Report of inspection which took place in March 2018)

This March 2018 inspection found that the provider had continued to build on the actions first identified during the inspection completed in April 2016 and that as a result, the centre was now in substantial compliance with the regulatory requirements.

Chapter 6. Social care needs

Introduction

Social inclusion for people with disabilities supports them to lead as normal a life as possible. People living in residential care should be supported to access the same opportunities as their peers and to regularly interact with their community, in line with their choice and wishes. It is only through interaction and inclusion that people with disabilities can develop lasting friendships and participate in social activities outside of the confines of the service.

The regulations set out the type of assessment and personal planning needed to guide care and support of residents. Proper assessment and personal planning is a critical feature in providing good quality care and support for people living in residential disability services, and this process should be undertaken in consultation with the resident.

Good social care and support are fundamental rights for people with disabilities and will ensure that they have equal opportunities to participate in meaningful and purposeful goals in the local and wider community.

Findings from inspections

One of the most critical components of social inclusion for people with disabilities is establishing and fostering lasting community-based relationships. However, initial inspections found that for some residents, there were limited opportunities for social inclusion, and in some cases, many recreational activities were being held on the campus of the centre rather than in the community. Findings from a number of inspection reports included:

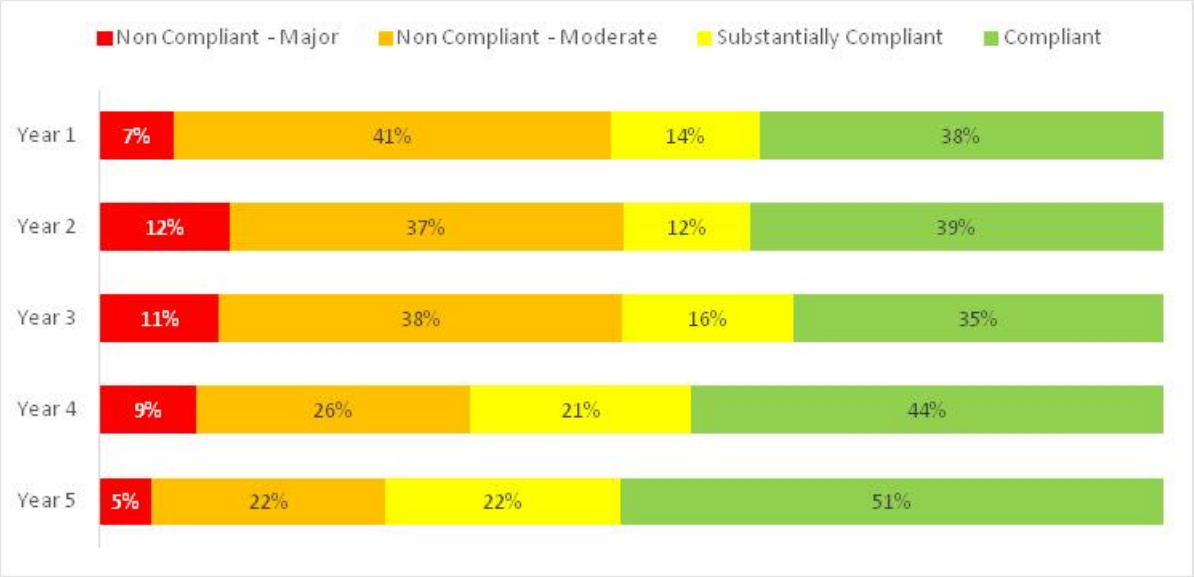
> "...residents had commented that they would [have] liked to [have] been offered more social activities while on their respite break and how the lack of transport inhibited their choices and in particular, when the weather was poor."

and

> "...a strong theme emerging from the feedback was the requirement for improvements in access for residents to the wider community and measures to improve community inclusion."

Improvements to the quality of residents' social care over the course of the five years of regulation were initially slow. While in many cases there were good examples of residents being able to access meaningful activities, it is only in the last two of regulation that there has been a significant shift in the levels of compliance in this area.

Figure 10. Compliance with the regulation on residents' social care needs, November 2013 to October 2018



Note: Year 1 includes November and December 2013 and all 2014; Year 5 is to the end of October 2018.

Figure 10 shows findings in this area for years one to five based on the inspections conducted during those years. In centres that were found to be compliant with the regulations, a common finding was that providers had ensured comprehensive assessments were completed in consultation with the residents. These assessments had effectively identified what social goals were important to residents and the support residents required to achieve these goals. There was also good evidence that providers had established clear plans of action and put the required resources in place to support residents in achieving these goals, and therefore meaningfully improve their lives.

For some residents who previously had limited opportunities for social inclusion and to share ordinary public places just like any other citizen, this shift in service delivery significantly supported greater community presence and indeed enhanced their self-esteem and their independence. This in turn promoted better quality of life outcomes. An inspection carried out in 2018 found that:

> "Residents described what it was like to live in the centre and how they were supported by staff to spend their time engaging in activities of their choosing. Residents who spoke with the inspector described how important it was to them to travel to work independently and use local public transport links."

However, while a significant majority of providers had made such improvements in establishing meaningful community-based relationships for residents, as highlighted above, a sizable number of providers (just over one in four or 27%) have not been as successful. Therefore, further work is required to ensure that all services provided

to residents are person centred and able to effectively meet their assessed social care and support needs on a continual basis.

Case study 3 — The impact of good social care

The centre is a large campus-based setting and provides residential and day support services for people with a range of disabilities. In 2013, at the point regulation of the disability sector commenced, the centre was deemed registered as a single designated centre, and could accommodate up to 47 residents across seven units. In 2016, and following a reconfiguration by the provider, the centre split into four separate designated centres, although these designated centres continued to be operated from within the original campus buildings.

The first inspection of the centre was completed over four days in October 2014. During this inspection it was identified that the centre was operating within an institutional model, resulting in a poor quality of life for residents and limited opportunities for social care activities or engagement in the wider community. For example, many of the services in the centre were provided centrally, including meals, laundry, pharmacy and the management of residents' finances. Daily routines in the centre were focused on staff breaks and the delivery of meals to the different areas of the centre.

Inspectors found that the institutional nature of service delivery in this centre was negatively impacting on the rights and safety of the residents, their social care needs and the management of their medication. Inspectors found that the layout of the building and the use of dormitory style rooms for residents meant that there were limited opportunities for privacy. In addition, the staffing allocation meant that residents were not always able to have active lives and be involved in community-based activities of interest to them. As a consequence, many of the residents would either stay in the communal areas of the centre or attend the on-site day service, with many residents never having the opportunity to leave the centre, to experience their local communities or interact with people outside of those employed by the provider. Following the inspection, the provider was required to set out how they would take action to improve the quality of life for residents in their response to the inspection findings.

In June 2015, an unannounced follow-up inspection was completed and while some improvements had been made to the centre, such as the transition of five residents into a community home, inspectors found that overall there had been a deterioration in the quality of life for residents living in this centre. The provider had failed to take the actions they had stated in their previous action plan and there continued to be an institutional approach to the delivery of care and support tasks within the centre,

due to poor staffing levels and a lack of access to activities of interest for the residents. Inspectors saw that residents were being left in their bedrooms behind closed doors, while waiting to go to their day activity, and some of the residents were displaying signs of distress such as

> '...calling out to staff and pulling at the curtains in their rooms'
>
> (Report of inspection which took place in June 2015)

This situation was compounded by the provider taking the decision to admit two further residents with complex needs to the centre without increasing the overall staffing levels in the centre. During the inspection, and due to the significant concerns about the provider's fire safety arrangements, the provider was issued with an immediate action requiring them to improve fire safety in the centre. In light of the living conditions in the centre, with continued reliance on multi-occupancy rooms, and the staff-to-resident ratio, the provider also advised the Chief Inspector that there would be no further admissions to the centre, in line with their plans to de-congregate the designated centre by 2020.

A further unannounced inspection was completed in March 2016. This time frame was set in order to provide adequate time to the provider to address the areas of non-compliance noted in the June 2015 inspection. During the inspection the inspectors again found that, while there had been some improvements made in the centre, the provider had failed to take adequate actions to address the deficits identified in June 2015. Residents continued to experience institutional practices, which were resource led and failed to ensure each resident's individuality. Staffing deficits, with no clear plan to fill these posts, meant residents were spending even more time in the centre and were unable to achieve their personal goals and outcomes.

The inspector concluded that the provider's governance and oversight arrangements in the centre were inadequate and required significant improvement. As a result of the inspection findings a warning letter was issued to the provider, requiring them to take action to bring the centre into compliance with the Health Act (2007) (as amended) and the regulations. Senior representatives of the provider were subsequently required to attend three regulatory meetings with the Chief Inspector to discuss the requirements for effective change in the centre and the improvements required in relation to the governance and management of the designated centre. In addition, the provider was required to submit a clear plan for the de-congregation of the centre.

In August 2016, a further unannounced inspection was completed to monitor the actions the provider had taken to improve the quality of life for residents living in the centre. However, once again, the inspectors found that while the provider had taken some action since the last inspection, that these had not positively impacted on the life of residents and, as a result, they continued to experience poor quality of life and institutional practices in the centre. In addition, the inspectors found that the governance arrangements in the centre continued to fail to address these concerns and were judged to be ineffective. Due to the continued failure of the provider to address the regulatory non-compliances noted over the four inspections, and the impact of these failings on the quality of life for residents, a decision was made by the Chief Inspector to issue a Notice of Proposed Decision to Cancel the registration of the centre on the grounds that the provider was not fit and they had failed to operate the centre in compliance with the Health Act 2007 (as amended) and the regulations made thereunder.

In line with legal process, as set out in section 54 of the Health Act 2007 (as amended), the provider had 28 days in which to make written representations to the Chief Inspector in respect of the noticed of proposed decision to cancel the registration of a centre. The provider made this representation in September 2016 and set out the actions it had taken to improve the governance and management of the centre (by reconfiguring this centre from one centre into four) and the improvements that had been made to the quality of life for residents.

In response to this representation, a further inspection was undertaken in December 2016 in order to determine the overall impact of these changes on the quality and safety of this service. Inspectors found that while work to bring the centres into compliance with the regulations was continuing, there had been a significant improvement in the quality and safety of life for residents. In particular, inspectors were told by resident that they

> '...were involved in the running of the centre...[and] were able to exercise choice and control in their daily lives'.
>
> (Report of inspection which took place in December 2016)

Inspectors found evidence that residents were being actively engaged in community activities, achieving individualised goals and were happy with the support they were receiving. For example residents had recently entered a painting competition held in the local community, residents showed the inspector the painting which had been hung in their communal lounge and told the inspector that they were:

'...proud of their paintings and had recently won a painting competition'

(Report of inspection which took place in June 2015)

In January 2017, and given the significant improvements found during the last inspection, the Chief inspector deferred the decision on the registration of the centre to allow the provider more time to implement their improvement plan. Between January and October 2017, two further inspections of each centre were completed in order to monitor the provider's progress towards implementing their improvement plan. The provider was also required to submit monthly updates to the Chief Inspector on the progress they were making to improve the quality and safety of the services. In addition, the provider was required to attend three provider meetings in order to give a verbal update on the progress of their quality improvements across all of their centres in the region.

The effect of this programme of regulation was evidenced in the overall improvement in the level of compliance across the four centres on the campus. Residents told inspectors that they were now *'very happy living in the centre'* and talked about the numerous activities and events that they had participated in and were looking forward to. The provider had made significant improvements to the environments and inspectors found that this had a significantly positive impact on the rights and dignity of the residents, and meant that they were able to enjoy their privacy. While the provider was continuing to work towards the de-congregation of this centre, in January 2018, and given the significant improvements made in the centre, the Chief Inspector made the decision to withdraw the notice of proposed decision to cancel the registration of the campus, and to register each of the four centres as standalone units.

Chapter 7. Health and safety and risk management

Introduction

Fit providers actively consider risk management and health and safety, and are responsive to changing risks. Providers must appropriately manage risks to the safety of residents and ensure that control measures are proportionate to the risk identified. Risk management is not about eliminating risks, but rather enabling residents to take risks in an informed way in order to lead fulfilling lives. Providers must therefore consider the potential negative impact that such control measures may have on the quality of life for residents.

Findings from inspections

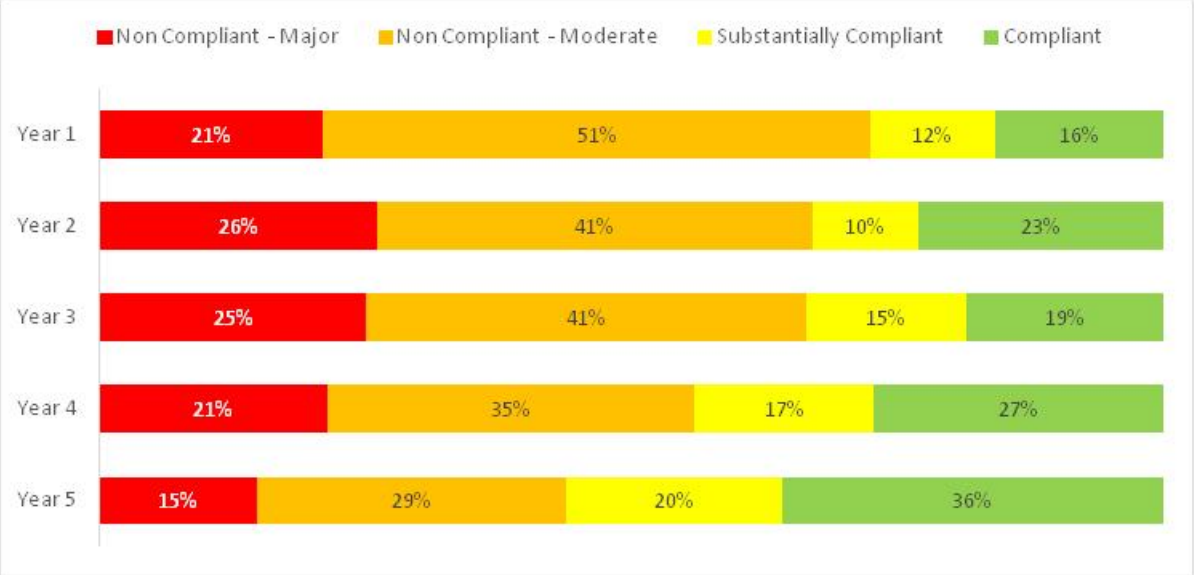
When regulation started in 2013, it was immediately clear that significant improvements were required to the health and safety and risk management systems in most designated centres for people with disabilities. The absence of measures to assess, control and mitigate risks within many designated centres, and a failure by providers to ensure their approach to risk management reduced risks to residents and staff, highlighted a lack of understanding of effective procedures in this area within designated centres.

As shown in Figure 11, while there has been a positive shift in compliance against regulations (in centres inspected) related to health and safety and risk management, this area continues to need improvement across a significant proportion of designated centres in the sector. A number of early inspections carried out by the Chief Inspector found that some services had:

- inadequately identified the measures and actions required to control risk
- inadequate arrangements in place to ensure that risk-control measures were proportional to the risk identified
- inadequate systems in place for the ongoing assessment, management and review of risk.

In addition, analysis of the first five years of regulation of designated centres for people with disabilities shows continued and repeated poor compliance with the regulations on health and safety and reducing risks in the centre. This includes issues around fire precautions and fire safety, such as managing the risk of fire in centres and addressing infrastructural deficiencies identified by independent fire-safety experts. As a result of ongoing non-compliances in relation to fire safety, the Chief Inspector has raised this issue with the HSE and the Department of Health.

Figure 11. Five-year findings on compliance with the regulations on health and safety and risk management, November 2013 to October 2018



Note: Year 1 includes November and December 2013 and all 2014; Year 5 is to the end of October 2018.

Inspections have also found inadequate management of and learning from adverse incidents, with some services focusing solely on keeping residents safe and making paternalistic decisions on behalf of the person in doing so, which impacted negatively on their autonomy. This approach to risk management resulted in residents being completely dependent on the service and led to an increased use of restrictive practices. For example, where it was deemed that the risk of financial abuse was too great, some residents were denied the right to manage (with support if required) their own financial affairs.

In some centres, where it was considered that a part of the living environment posed too great a risk for residents to use (such as the kitchen), access to this room was denied. Other examples included where it was deemed that the risks associated with travelling independently on public transport were unacceptable, residents had no choice but to rely on transport provided by the service to access their community and their various day-service placements or jobs.

Therefore, whenever the measures used to manage risk were found to be disproportionate and over-protective, people with disabilities were denied their right to self-determination, social inclusion and opportunities for new experiences. Studies show that paternalistic decision-making can lead to 'silent harms' where the person with a disability is physically safe but their quality of life is diminished.[27] The result is that the service 'disempowers' the person, making decisions on the person's behalf as it believe it is acting in the person's 'best interests'.

Improvements in how services managed risk

To support providers and staff to consider a more responsive and positive approach to risk management, HIQA published two guidance documents: *Guidance for Designated Centres – Risk Management* in 2014 and *Supporting People's Autonomy – A Guidance Document* in 2016. Due to the publication of these guidance documents and increased focus on these issues through inspections of disability services, some improvements in how services were managing risk were seen in 2017 and 2018 inspections.

Improvements included a process of risk assessment that was more dynamic and proactive in identifying mitigating factors to reduce the level of risk associated with specific activities and in promoting residents' autonomy, empowerment and opportunities for new social and learning experiences. In some instances, residents were supported to learn new skills, such as travelling independently in the community or travelling to work. In doing so, the residents were not only learning about the risks associated with such an activity but were also provided with the skills and knowledge required to manage and mitigate such risks.

Positive risk taking is all about enabling people with disabilities to have autonomy over their own lives, in turn improving the overall quality of their lives. Inspectors noted that where services supported residents to learn new skills, such as independent travelling and doing their own laundry or cooking, these residents appeared to have good self-esteem, loved to share their stories with the inspectors and, most notably, were very proud of their significant achievements.

Of the centres inspected, the data shows that over the first five years of regulation, there have been high levels of non-compliance (either major or moderate) with the regulations across those centres inspected on health and safety and risk management. These non-compliances are particularly acute in the area of fire safety, where providers have failed to ensure that there are adequate arrangements in place for detecting, containing and extinguishing fires. In addition, in many centres, residents present with specific support needs in the event of a fire. For example, refusing to leave the building or requiring additional supports to evacuate. In these circumstances, the arrangements to assess and put in place individualised support plans — which enable a safe and timely evacuation from the designated centre — have often been found to have been inadequate.

Independent fire-safety experts, acting on behalf of providers, have found that urgent fire-safety upgrade works are required in a large cohort of centres. Providers were required by the Chief Inspector to put additional measures in place to mitigate related fire-safety risks and have fire-safety experts confirm that these measures had been put in place, pending the required upgrade works being completed. While

providers have been addressing these issues incrementally, significant capital investment in services is needed to address these requirements. In the interim, the Chief Inspector continues to monitor the risks to residents in these services until such time that these risks have been comprehensively addressed.

While a number of designated centres have yet to improve how they are managing risk, many inspections of residential services have found that services have embraced the regulations and are using the risk guidance documents published by HIQA to better manage this complex area and improve the quality of life for people with disabilities. **Case study 4** considers how the poor management of risk led to the cancellation of a centre's registration.

Case study 4 — The impact of an unfit provider

This case study relates to two houses which were both separate designated centres providing services to adults with autism. All related inspection reports have been published by the Chief Inspector.

The centres were founded by a group of parents of children with autism. Both centres were in rural locations and comprised several units consisting of a mix of bungalows, cottages and two-storey dwellings. In addition to the residential units, both centres had made provision for a range of activities on site: a horticultural centre, greenhouse, woodwork and pottery workshops. Day services were also available. Between them, they had the capacity to accommodate 20 adults for both full-time, part-time and respite services. Both centres were operated by the same registered provider.

The first inspections of these centres, completed in 2015, uncovered a range of concerns regarding the quality of life and safety of the people who lived there. Inspectors found that there was a tense atmosphere in the centres because residents who did not get along were placed together in the same accommodation.

In addition, residents were not able to access some social activities because of staff shortages. There was an over-reliance on relief staff which meant that residents were being supported by different people frequently — therefore, there was little continuity of care and support. The buildings were also noted to be in a poor state of repair. Inspectors identified serious deficiencies in the governance and management arrangements of the registered provider.

These concerns were reflected in an inspection report:

> "A number of staff members and relatives spoken with during the inspection expressed concern that staff shortages and unfamiliar staff were impacting on the availability of opportunities for outings, and in particular two to one activities for residents. For example, staff informed inspectors that a recent outing scheduled to finish at 17.00 had to be cut short to 15.00, as staff were required to return to the centre to cover staff shortages."
>
> (Report of inspection which took place in October 2015)

Inspectors monitored both centres closely between 2015 to 2017 while the provider implemented its improvement plans. The centres were subject to a number of inspections which found that where the provider had made improvements, it had failed to sustain them, and in 2017 there continued to be high levels of non-compliance, which was negatively impacting on the lived experience of residents in both centres.

In addition to inspection activity, the Chief Inspector received a number of concerns in relation to both centres during 2016 and 2017 from members of the public.

Given the persistent nature of the non-compliances found on inspections and the inability of the registered provider to improve the quality of life for residents, the Chief Inspector issued to issue notices of proposal to cancel the registration of both centres in February 2017.

In response to the notices, the provider made a representation to the Chief Inspector setting out why the registration of the centres should not be cancelled and how they intended to improve. Inspectors undertook further inspections and found continued poor management and oversight of the centres. The registrations of both centres were cancelled in May 2017 as the quality of life and the safety of residents was deemed to be unacceptable. Whenever the registration of a designated centre is cancelled, the HSE is required under the Health Act 2007 (as amended) to take over the operation of the centre. In both cases, the HSE, under section 64 of the Act, took responsibility for operating the centres.

Later inspections of the centres noted considerable improvements in the quality of life of residents. Inappropriate placements which had caused conflict between residents had been addressed and peer-to-peer incidents reduced. Residents were noted to be engaged frequently in meaningful activities of their choosing. Inspectors communicated with residents who said or indicated that they felt safe and happy in their homes:

"The residents were very comfortable in the presence of staff and with the support they were providing. Some residents communicated in a non-verbal manner and therefore could not tell the inspectors their opinions of the service. However, the inspectors observed residents and noted the positive interactions that took place between residents and staff. Other residents communicated very clearly that they were happy residing in the centre and with the care and support received. Residents were seen to be relaxed in the company of staff and there was a warm atmosphere in this home throughout the inspection."

(Report of inspection which took place in December 2018)

The upkeep and maintenance of the physical premises had also markedly improved. While the HSE continues to be the registered provider, it is at the time of writing in the process of identifying a new registered provider to take over the running of the centres.

Chapter 8. Governance and management

Introduction

Regulation of social services has shown that where good governance and management arrangements are in place, the quality of support and care is also good. In these cases, the centre is usually well run and managed by the registered provider and by the person in charge.

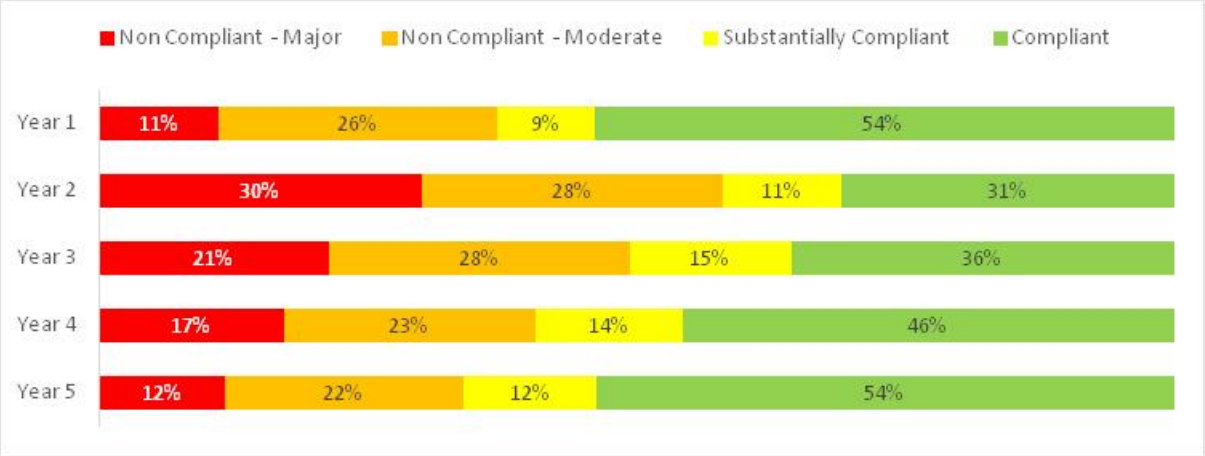
However, where there are inadequate governance arrangements, invariably the provider struggles to sustainably ensure a high-quality service for residents. Poor governance has a direct impact on the lived experiences of residents, leading to poorer outcomes for them.

Compliance in this area of the regulations is a principle characteristic of a service's quality and safety.[(28)] The regulations require centres to have a clear management structure and clear lines of authority and accountability. They also specify the requirement to have a designated person in charge with appropriate skills and qualifications for running the centre. How a provider oversees, governs, monitors and evaluates its services is a fundamental assurance mechanism of the quality and safety of those services. These measures enable a service to continually improve by identifying things it could be doing better, and taking action to improve service delivery.

Case study 5 in this chapter demonstrates the real effects of poor governance on residents' lives, and shows regulation in practice, with corrective actions taken when this was identified.

In Year 1 of regulation (as seen in Figure 12), while some providers had developed and implemented effective governance systems, significant improvement was required in the area of governance and management across the sector. By Year 2, as more centres were inspected, it was evident that significant improvement in the governance arrangements in designated centres were required, with 58% of centres inspected failing to achieve a basic level of good governance. Since Year 3, this has steadily improved but good governance continues to be an area which some providers continue to fail to make sustained improvement. This area continues to require significant focus from providers, as demonstrated in the compliance findings from 2018.

Figure 12. Five-year findings on governance and management, November 2013 to October 2018



Note: Year 1 includes November and December 2013 and all 2014; Year 5 is to the end of October 2018.

In the first two years of regulation, a number of common governance and management issues were found to impact negatively on the quality of life of residents. For example, in some services, the person in charge had a vast remit with responsibility for the oversight and day-to-day operational management of multiple centres. In some instances, this resulted in the person in charge being overstretched, with inadequate protected management hours to effectively manage each centre they had responsibility for.

Where this was the case, the person in charge was not carrying out their duties in a timely manner to ensure the smooth and effective delivery of the service. Services were susceptible to greater levels of non-compliance with the regulations because they were:

- not being effectively monitored
- not appropriately supervising staff
- not reviewing care plans in a timely way
- inadequately maintaining critical documentation that informed practice.

When deficits in care where identified, good providers recognised that change was required in their governance and oversight arrangements, if they were to fulfil their legal obligations to the residents, and took corrective actions to resolve matters. For example, some providers responded by reviewing the remit of their persons in charge. Where they determined that these managers had inadequate protected management hours to carry out their duties, they reduced the number of centres these managers had responsibility for. In some instances, providers identified and

promoted staff members to support the role of person in charge, so as to enhance and strengthen the overall management structure and daily oversight of the centre.

Furthermore, many providers introduced better and more effective systems of auditing as a consequence of inspections and regulatory activity. In these centres, inspections in 2017 and 2018 found that, for the most part, residents appeared happy and content. This was because providers of these services were now ensuring that there were clearly defined and effective management structures in place which were responsive to meeting residents' assessed needs.

However, the level of overall complaince in those centres inspected in 2018, in relation to the provider's governance and management arrangements, remains low, and continues to have a negative impact on the overall quality and safety of residents living in those services. As discussed later in this report, the Chief Inspector has a range of legal powers available in order to compel providers, who are consitently failing to achieve compliance in their services, to take improvement actions. For instance, at the end of October 2018, additional restrictive conditions had been attached to the registration of 117 centres, which required the provider to implement targetted improvement actions within an agreed time frame. These actions may vary in nature, for example, to restrict admissions to a centre to ensure that the provider makes necessary changes to the safety of the environment prior to admitting any other residents, or specific actions relating to fire safety, requiring the provider to implement the recommendations of a fire safety report that they were required to comission as a result of findings from an inspection.

In many cases the issues resulting in the Chief Inspector attaching these conditions had been identified during the course of the inspection process, which highlighted that the provider had failed to self-identify these issues or their impact, through their own surveillance and oversight arrangements. It is imperative that providers continually review the effectiveness and adminstration of their governance and oversight arrangements to ensure that they are consitently and confidently able to rely on the information they gather about the quality and safety of their services.

Given the overall complaince level in governance and management found during the course of the first five years of regulation in the sector, inspectors will continue to focus on this area to ensure providers are improving their goverance and management arrangments.

Key findings in relation to governance

It is clear that the fitness of the registered provider and managers and their openness to operate in a regulatory environment was a key factor in delivering a safe, quality service to people with disabilities. The registered provider being unfit to

fulfil their duties was a significant factor in the 10 cancellations of registration during the first five years of regulation.

Notwithstanding the difficulties and challenges faced by registered providers to comply with regulations and improve the quality and safety of services, there is evidence to show that matters improved as time progressed. The data on overall compliance with regulations across the first five years of regulation (Figure 7) shows that there was a gradual improvement year-on-year. However, the levels of non-compliance in relation to governance and management remain a cause for concern.

Case study 5 — The effect of governance on meeting the regulations

All inspection reports in relation to this case study have been published by HIQA. At the commencement of regulation in November 2013, this provider was providing residential services to 80 adults and children with physical, intellectual and sensory disabilities in campus-based designated centres. This case study relates to one campus-based setting.

Initially, inspections between 2014 and 2015 found high levels of non-compliance in key areas, including risk management, fire safety, premises, safeguarding and social care supports, all of which were impacting negatively on the privacy, dignity, safety and quality of care provided to the residents. Residents' right to choice and self-determination were limited in many ways. For example, residents were unable to freely move about their homes or go outside independently if they wished. In some instances, residents had not left the campus setting for many years.

Activities for residents took place exclusively on the centre's campus, which was located in an isolated setting away from the local community. This meant that residents were not provided with opportunities to experience integration and experiences in their own local community where they lived. Opportunities for residents to experience sunlight and fresh air were limited, and only occurred when staff engaged them in an activity outside within the grounds of the campus.

> "During the inspection residents were observed spending long periods of time not engaged in any meaningful activities throughout their day. Residents were observed by inspectors sitting for long periods in their rooms and communal areas without any interaction with staff. It was unclear from reviewing resident's personal plans if their wishes and aspirations regarding training and education were known or that this was assessed or explored on behalf of the residents as there was no supporting documentation available".
>
> (Report of inspection which took place in June 2015)

Residents' living conditions were inadequate and highly restrictive. For example, kitchenette areas were locked to prevent all residents from accessing these areas due to safety concerns for some residents. In other instances, residents were confined to a specific 'wing' of their residential unit and unable to freely move throughout the premises in what was a very poor living environment:

"Inspectors found the premises to be substandard and very poorly maintained and not fit for its stated purpose. There were sinking floors in one unit and flooring in disrepair throughout all other units. Some items of furniture were held together with duct tape and many wardrobes and other items of furniture requiring replacement. Paint was peeling from the window frames and chunks of wood were missing from some windows. Doors and walls in many areas inside required painting. Many doorways internally were in very poor condition as they were narrow and wheelchairs could not fit through with ease therefore door frames had been badly damaged. Ceilings in many areas were damp with water stains. The centre was visibly unclean in all areas. Visible layers of dust were present throughout the centre."

(Report of inspection which took place in June 2015)

Regulator takes action

During 2014 and 2015, the Chief Inspector provided the organisation with an opportunity to address the areas of non-compliances found on inspections. However, major non-compliances continued to be found on the campus and towards the end of 2015 notices of proposal to cancel the registration of the campus-based centre were issued to the provider. Furthermore, the Chief Inspector went to the relevant local district court in line with sections 59 and 60 of the Health Act 2007 (as amended), on foot of serious concerns regarding fire safety arrangements in one of the houses on the campus.

The registration of the designated centre was cancelled in June 2015 in line with section 64 of the Health Act 2007 (as amended); the Health Service Executive (HSE) became the registered provider of this particular designated centre. The original registered provider made representations to the Chief Inspector against the remaining notices of proposal to cancel the registration of the other centres on the campus, with further representations made in 2016 relating to changes to the management structure and governance arrangements of the organisation.

Impact of regulation

From June 2016 until January 2017, an intensive inspection process was undertaken to assess the fitness of the provider and the effectiveness of its new governance arrangements and management systems. These inspections found that the provider was improving its governance arrangements and assurance mechanisms, and as a result was able to better meet the individual needs of the residents. Significant refurbishment and reconfiguration works had been carried out on the campus and

staff were up-skilled in a particular model of social care. In addition, key managers had been appointed to establish and promote a person-centred culture within the organisation. The provider also recognised that the de-congregation of the campus, into community-based houses, would provide the best possible outcomes for residents and improve their quality of life.

Inspectors found that this governance change resulted in a reduced level of environmental restrictions being used on the campus and better arrangements for residents in the centre while they were waiting to move to their new community-based homes. Arrangements for residents' privacy and dignity and arrangements to support residents with their health and nutrition had also been improved. The regulatory interventions of the Chief Inspector had improved the residents' overall quality of life:

> "Since the previous inspection some improvements had begun with regards to ensuring residents' healthcare needs were assessed within an allied health professional framework and there evidence to indicate the provider was actively trying to provide less institutional practices with regards to residents' nutrition and meal preparation…. Residents' evening meals were cooked in the designated centre at least twice a week. Residents could now have a choice for their breakfast, for example the option of a freshly cooked breakfast was now an option…. A resident, that had refused to leave their bedroom to eat their meals with other residents, now enjoyed a cooked breakfast in the morning and was sitting having their other meals with their peers more often."
>
> (Report of inspection which took place in December 2016)

In April 2017, the provider registered its first community residential centre as part of a programme to enable residents to move out of the congregated setting into more appropriate residential services. By 31 December 2018, the provider had registered 14 community residential centres with 20 residents remaining within the campus-based designated centres. At the time of writing, the full de-congregation of the campus was projected to be completed by July 2019. HIQA inspection reports have subsequently noted that this de-congregation progress has resulted in significant, tangible improvements in the quality of life and health of residents.

Chapter 9. Escalation and enforcement

Escalated regulatory activity

Over the first five years of regulation, the vast majority of centres for people with disabilities were granted registration with conditions placed on their registration. However, in some cases, the Chief Inspector took escalated regulatory action against a number of providers. This included issuing warning letters to providers, requiring them to take action to bring their centres into compliance with the regulations. For the vast majority of those centres, this type of escalated regulatory action resulted in the provider taking the necessary actions to improve the quality of the service being provided to people living in the centre and to meet the regulations.

However, other providers required further action, including developing a regulatory plan for the provider at organisational level to address poor oversight and governance of services or placing conditions on a centre's registration.

Following these actions, providers of 68 designated centres failed to make sustained improvements that would improve the quality of life for residents, and this, together with a lack of assessed fitness on behalf of the provider, resulted in the Chief Inspector issuing notices of proposed decision to cancel the registration of these 68 centres. Prior to making a proposed decision, these providers were given numerous opportunities to improve their service through a regulatory plan. Where notices of proposed decision to cancel are issued, the provider has 28 days to make representations to the Chief Inspector, setting out in writing the action that it will take or intends to take in order to improve the services.

Each centre is closely monitored to validate whether the actions that the provider stated they would take through their written representation to the Chief Inspector had improved the quality of life and safety for residents. A significant number of providers who received such notices successfully addressed the issues in their centres, the notices of proposed decision to cancel the registration were withdrawn in 51 of those centres. Other centres either closed or re-configured and applied for registration as a new service.

However, the Chief Inspector progressed to make a decision to cancel the registration of 10 centres where the provider had failed to adequately and sustainably improve the safety and quality of life for residents and demonstrate that it was a fit provider.

Cancelling the registration of a designated centre is a serious decision and only made when the risk to the residents is unacceptable because:

- the provider has failed (despite being given an opportunity) to improve its service in order to comply with the regulations and national standards
- the provider or person participating in management is no longer considered to be a fit person
- the provider or person participating in management is no longer considered to be a fit person where the provider has been convicted of a criminal offence as outlined in the Act.

The grounds for cancelling each centre's registration were specific to the circumstance of each designated centre. However, for all of them, the registered provider was found to be unfit to be involved in the running of that centre. Guidance on how fitness is assessed and determined can be found at www.hiqa.ie.

Under section 64 of the Act, once the registration of a centre has been cancelled, the HSE is required to take over its operation as if it was the registered provider while the HSE makes alternative arrangements for the residents. Table 1 identifies the 10 centres where the Chief Inspector issued a notice of decision to cancel registration between the commencement of regulation in late 2013 and October 2018.

Table 1. Providers issued a notice of decision to cancel registration by the Chief Inspector

Centre name	Provider organisation	Enforcement decision on registration
2015		
Our Lady's Centre	Saint Patrick's Centre (Kilkenny)	Cancelled. HSE operating centre under section 64 of Health Act 2007 (as amended)
Dunfirth Farm	The Irish Society for Autism	Cancelled. HSE operating centre under section 64 of Health Act 2007 (as amended)
Cluain Farm	The Irish Society for Autism	Cancelled. HSE operating centre under section 64 of Health Act 2007 (as amended)
Sarshill House	The Irish Society for Autism	Cancelled. HSE operating centre under section 64 of Health Act 2007 (as amended)
2016		
St Laurence Cheshire	The Cheshire Foundation in Ireland	Cancelled — new provider arranged by HSE
St. Vincent's Centre	St Vincent's Centre Ltd	Cancelled. HSE operating centre under section 64 of Health Act 2007 (as amended)
Camphill Community Ballytobin	Camphill Communities of Ireland	Cancelled. HSE operating centre under section 64 of Health Act 2007 (as amended)
2017		
Greenville House	Cork Association for Autism	Cancelled. HSE operating centre under section 64 of Health Act 2007 (as amended)
Crobally	Cork Association for Autism	Cancelled. HSE operating centre under section 64 of Health Act 2007 (as amended)
2018		
The Bridge Community 2	Camphill Communities of Ireland	Cancelled. Closed permanently

Chapter 10. Challenges and conclusions

The Chief Inspector within HIQA commenced regulation of residential services for people with disabilities on 1 November 2013; marking the first time such services were subject to independent regulation.

The majority of providers and staff responded positively, taking significant steps to comply with the regulations and to improve the quality of their services. This has resulted in positive outcomes for people with disabilities living in these centres.

As evidenced throughout this report however, poor levels of compliance in the early years reflect a sector that was not prepared for regulation in November 2013. There was a risk that, with the deadline for the registration of all centres set for 31 October 2016, approximately 350 centres (or one in every three centres) would be refused registration due to high levels of non-compliance. This would have had serious negative consequences for thousands of people living in these centres.

Intervention by the Chief Inspector led the Minister for Health to extend the time frame for registration for another two years,[(29)] allowing time for regulation to drive improvements for residents. Data from the past two years shows regulation in action, with compliance with all regulations inspected increasing from 59% in Year 1 to 76% by Year 5. By 31 October 2018, 1,183 centres were registered.

Regulation has increased awareness of what life is like in residential care for people with disabilities and has driven sustained improvements to the quality of life and experiences of many people living in these centres around Ireland. Despite this, challenges still remain in addressing key areas of the regulations and infrastructure, planning for future regulation of services, and ensuring that the voice of residents is heard and reflected in how centres are operated and how HIQA and the Chief Inspector conducts its work.

Continuing areas of concern

Inspection findings demonstrate the critical importance of good governance in ensuring sustainable and good quality services, where the resident is always at the centre of the service. This is particularly evident where providers effectively monitor and evaluate their services and assure themselves that improvements are being made where necessary.

However, five years on from the start of regulation, it is clear that some providers' governance arrangements have continually failed to ensure there is adequate oversight of the quality and safety of their services. As a result, they continue to struggle with complying fully with the regulations in relation to governance and management.

Inspection data also shows that where residents have moved from large campus-based settings into smaller individualised homes in the community, residents have experienced improvements to their quality of life.

Many residents have told inspectors that their lives have changed positively following these moves. With the continued move away from congregated and campus-based disability settings to community living anticipated in the coming years,[15, 16] a parallel increase in the number of newly registered or reconfigured designated centres is expected.

The introduction of safeguarding legislation will have a positive impact on the quality of lives for residents. In addition, safeguards for vulnerable people living in the community or in their own home will be further protected through the introduction of regulation across all homecare services and arrangements.

While newer, purpose-built community homes will provide better living environments and higher standards of fire safety for residents, there is presently a continued reliance on older premises which are unable to meet residents' changing needs.

Infrastructural challenges

The Chief Inspector is aware of ongoing challenges faced by some providers in achieving a safe and high-quality living environment for residents.

Many providers who continue to operate older premises have identified significant financial challenges in maintaining and improving these environments, with residents in some centres continuing to have limited opportunities for privacy in shared bedrooms. The sustainability of these buildings and the need to improve the quality of the living environment will no doubt require further evaluation and careful consideration by providers, particularly as people age within their current homes and when their home environments are no longer able to safely support their needs.

In many of these centres, funding for new infrastructure will be needed to improve the quality of accommodation in order to improve the quality of life of residents and ensure their privacy, dignity and safety.

By the end of 2018, 117 centres had been registered with additional conditions of registration which required funding for infrastructural work or renovations in order to meet those conditions. These were centres where providers had mitigated immediate risks to residents but where further improvements were required, for example, further fire-safety upgrade works.

These 117 centres also include centres where there is overcrowding or where residents who are unable to live together harmoniously continue to live together or

share bedrooms, despite the negative consequences on the quality of life for these residents and or others residents living in the same centre.

In addition, many residents continue to live in poorly maintained congregated settings, in buildings no longer fit for purpose, as they await a move to community-based living. The Chief Inspector will continue to raise this issue with the relevant authorities and will continue to highlight the negative impact that this is having on the people living in these centres.

Quality improvement

As the next cycle of registration begins, regulation will focus on driving improvements in specific aspects of the quality of services and support afforded to residents in designated centres for children and adults with disabilities.

'Thematic' programmes focus on a particular theme and are aimed at promoting quality improvement. Providers will be expected to use learning from thematic programmes to continually improve the quality of service in their centres, ultimately benefiting the people living there.

In early 2019, the first thematic programme was introduced in designated centres for people with a disability focusing on restrictive practices. At the time of writing this report, inspectors have completed 16 restrictive practice thematic inspections with more inspections scheduled. Reports of these inspections will be published in due course.

Good governance can be a complex issue with many providers continuing to struggle to reach full compliance in this area. In 2018, the Chief Inspector produced guidance on the assessment of fitness of people who are managing designated centres, including guidance on good governance to help providers meet these regulations.

As many providers move to another cycle of three-year registration, inspectors will continue to focus on improving compliance with the governance and oversight requirements in centres and on achieving ongoing quality improvement in services for the people who live there.

The voice of residents

The lived experience of residents is a key indicator of the safety and quality of a service; however, at times it has been a challenge to engage directly with residents. While the voices and experiences of residents continue to be sought during inspections, inspectors also recognise the importance of engaging with residents, their families, advocates and their representatives on an ongoing basis outside of the inspection process.

In recent years, inspectors have been meeting with residents' groups and local committees across the country. These engagements have focused on listening to residents' and families' views on how HIQA conducts its work. This work will be expanded going forward to ensure the people who use services have a voice in how their services are regulated.

The feedback gathered from these engagements informs improvements in inspection processes and how findings from inspections are reported.

Future regulation of services

Regulation of designated centres provides legal protection for the people who live there; however, HIQA is concerned that other vulnerable people are not provided the same protection under the law.

Research conducted by HIQA in 2017 asserted that the definition of a designated centre in the Health Act is very limited and does not capture all of the current and emerging models of care in Ireland for people with disabilities.[17, 18] All of these models have potentially vulnerable and dependent service users who should have the same legal protections as those currently living in designated centres.

There was a consensus among discussion groups for this research that a service-based model of registration, which has been introduced in Wales — coupled with regulations specific to each model of care — represented the best course for regulation into the future. Under such a system, a provider would be registered with the regulator rather than an individual centre or service. The Chief Inspector would agree that this is the best approach.

Such regulation of services would be a better fit for Ireland for a number of reasons, including allowing service providers to be more flexible and innovative, such as accommodating service users with different support needs in the same settings. The administration and burden of the registration cycle could also be reduced, both for the service provider and the regulator.

HIQA and the Chief Inspector are committed to working closely with the Minister for Health and the Department of Health to review and potentially amend the legal framework for the regulation of services for all vulnerable people.

Conclusion

The first five years of regulation have increased transparency about how services are run, and have often been the catalyst for continual improvement in the quality of services and in the lives of the people who live there. However, there continues to be a need for further improvements across the sector.

The Chief Inspector will continue to apply the current regulatory framework proportionately to improve the quality of life of residents living in residential care for people with disabilities. The Chief Inspector will also continue to advocate for the rights of vulnerable people to live full lives in their communities, in well-run, modernised pleasant surroundings which are safe, fit for purpose and designed to meet the changing needs of residents as they grow older.

Appendix 1 — Compliance with the regulations

Current judgments

In the current model of regulation, the following ways are used to describe compliance with regulations by providers:

Compliant means the provider and or the person in charge is in full compliance with the relevant regulation.

Substantially compliant means that the provider or person in charge has generally met the requirements of the regulation but some action is required to be fully compliant. This finding will have a low risk rating.

Not compliant means the provider or person in charge has failed to comply with a regulation and that considerable action is required to reach compliance. Continued non-compliance or where the non-compliance poses a significant risk to the safety, health and welfare of residents will be given a high-risk rating.

In such cases, we will set a deadline for the provider to comply with the regulation. Where the non-compliance does not pose a significant risk to the safety, health and welfare of residents using the service, it is risk-rated moderate risk and the provider must reach compliance within a reasonable time frame.

Previous judgment compliance classifications

Under the previous model of regulation, the Chief Inspector judged a registered provider or person in charge to be compliant, substantially compliant or non-compliant with the regulations and or standards. These had been defined as follows:

Compliant: a judgment of compliant means that no action is required as the provider or person in charge (as appropriate) has fully met the standard and is in full compliance with the relevant regulation.

Substantially compliant: a judgment of substantially compliant means that some action is required by the registered provider or person in charge (as appropriate) to fully meet a standard or to comply with a regulation.

Non-compliant - moderate or major: a judgment of non-compliant means that substantive action is required by the registered provider or person in charge (as appropriate) to fully meet a standard or to comply with a regulation.

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