



**Health
Information
and Quality
Authority**

An tÚdarás Um Fhaisnéis
agus Cáilíocht Sláinte

Regulation of
Health and Social
Care Services

Annual overview report on the inspection and regulation of disability services in 2019

2 September 2020

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.

Table of contents

About the Health Information and Quality Authority (HIQA).....	3
Introduction by the Deputy Chief Inspector of Social Services (Disability)	9
Chapter 1. Listening to the views of residents.....	11
1.1. Introduction to engaging with residents during inspections	11
1.2. Capturing residents' voices in the inspection report.....	12
1.3. What residents told us on inspection in 2019.....	13
1.4. The impact of compliance with regulations on residents' lived experiences and human rights.....	14
1.5. Engaging with residents outside of the inspection process.....	17
1.6. What we heard during group meetings of residents	17
1.7. Next steps in hearing from residents.....	19
Chapter 2. Analysis of regulatory compliance in congregated versus community settings	20
2.1. Introduction	20
2.2. Governance and management.....	20
2.3. Safeguarding	22
2.4. Social care.....	25
2.5. General welfare and development.....	27
2.6. Risk management	28
2.7. Fire safety	31
2.8. Premises	32
Chapter 3. A focus on human rights in the use of restrictive practices	35
3.1. Introduction to thematic inspections of restrictive practices	35
3.2. Findings of thematic inspections of restrictive practices.....	35
3.3. Next steps in thematic monitoring of restrictive practices	37
Chapter 4. Registration and inspection activity in 2019.....	38
4.1. Introduction to registration and inspection	38
4.2. The number and type of designated centres.....	38
4.3. The size of disability centres.....	40
4.4. Congregated settings	42
4.5. Registration activity in 2019	42

4.6. How compliance is judged	43
4.7. Inspection activity in 2019.....	44
4.8. Centres requiring repeat visits in 2019	45
4.9. Publication of inspection reports	46
4.10. Feedback on inspection reports and submissions	46
4.11. Notifications of incidents, events and changes	47
4.12. Information of concern	49
Chapter 5. Escalation and enforcement	52
5.1. Introduction to actions to protect residents	52
5.2. Provider warning letters and meetings	52
5.3. Attaching conditions of registration	53
5.4. Notices of proposed decision to cancel, refuse or attach.....	54
Chapter 6. Concluding statement	56
Bibliography	58

A message from the Chief Inspector of Social Services and Director of Regulation



Mary Dunnion, Chief Inspector of Social Services and Director of Regulation

I am pleased to present this report on the regulation of designated residential centres for adults and children with disabilities in Ireland. This report focuses on HIQA's work in these services during 2019 to improve the quality and safety of care for those who use them.

Significant progress has been made by providers since we commenced independent regulation of these services in 2013. This has required huge changes to the way some services are delivered and the allocation of additional funding to address immediate safety issues. Initially, we found many centres where residents had a good quality of life, but we also found many residents living in shocking conditions.

In those early days of regulation, many people with disabilities were not valued as citizens of this country and were living in large, old and poorly maintained buildings. We found that some providers were failing to prevent the risk of abuse and where it did happen, some providers were not always responding adequately to protect residents. In some cases, inspectors required providers to have their own fire safety experts to review premises, with serious fire safety shortcomings being identified.

While regulation has undoubtedly made a significant contribution to improving the lives, experiences and human rights of people living in these centres over the past six years, further work remains to be done. This overview reports shows that one in three residents continue to live in large institutions or campuses and are at greater risk of having a poor quality of life compared to residents who live in community settings.

Primary responsibility for providing a safe and a good quality service to people with disabilities rests with the service providers. However, it is also imperative that the funders of these services ensure that public finances are being used to deliver a good quality and safe service. We are pleased to report that throughout 2019 the majority of services continued to improve, with our inspectors finding positive outcomes for residents in key areas such as social care, safeguarding, residents' rights, governance and risk management.

However, it is disheartening to report that we continued to find people with disabilities living in designated centres who could not fully exercise their human rights — a key feature of person-centred care. Everyone who works in health and social care services is responsible for ensuring that these rights are upheld.¹

During 2019, the quality of life and the lived experiences of many residents living in campus or congregated settings² continued to lag significantly behind that of residents living in smaller community-based centres, such as houses in towns or rural areas. Residents in congregated settings were often separated from their local communities and continued to live in unsuitable, outdated accommodation. Important aspects of everyday life, such as the privacy of your own room, being able to have local friends, and having access to your own kitchen or laundry facilities are often compromised or unavailable to residents in many congregated settings. We continue to prioritise applications to register new centres to support the transition of these residents to better living arrangements.

Listening to residents' voices during inspections is crucial in how we determine service performance. In 2019, we continued to seek the views of residents, both during inspections and outside of the inspection process.

Since we began regulating residential disability services in 2013, many new types of service have been developed, which we welcome. However, these new models do not fit easily with the definition of a designated centre as set out in the Health Act 2007 (as amended). This is leading to increasing numbers of people with disabilities receiving care and support which is outside the scope of current legislation, and hence not protected through regulation. We continue to engage with national policy makers on regulatory reform in this area. We will also continue to use regulation to support national policy of people moving to more appropriate, community housing, as well as to improve the safety and quality of life for residents who are still living in congregated settings while they are waiting to move to better places to live.

As I write this message, the challenges and impact of the COVID-19 pandemic continue. I am encouraged by the engaging approach taken by providers, staff, residents and their families to managing and reducing the risk of significant outbreaks of COVID-19 in designated centres for people with disabilities. We are committed to continuing to work with providers during these challenging times to ensure that the rights of residents are promoted and protected. We will also endeavour to capture residents' and families' view, on both services and how we inspect, while the public health emergency continues.

¹ For further reading, see <https://www.hiqa.ie/sites/default/files/2019-11/Human-Rights-Based-Approach-Guide.PDF>

² Large institutions or clusters of accommodation on the grounds of institutions.

I want to acknowledge the ongoing support and cooperation of providers and staff during our inspections, many of whom work diligently with residents and families to provide safer and better services. Finally and most importantly, I would like to thank the residents, their families, friends and advocates for the assistance and time which they give to our inspectors when they visit their homes.

A handwritten signature in cursive script, reading "Mary Dunnion".

Mary Dunnion

Chief Inspector of Social Services and Director of Regulation, Health Information and Quality Authority

Introduction by the Deputy Chief Inspector of Social Services (Disability)



Finbarr Colfer, Deputy Chief Inspector of Social Services (Disability)

Welcome to our latest overview report on the regulation of designated residential centres for adults and children with disabilities in Ireland. During 2019, we monitored compliance with regulations and national standards across 1,268 centres. This report highlights examples of good practice and areas where improvements are still required, and where people with disabilities in residential services are still restricted from exercising their human rights equally. We hope providers can use this report to help improve the lived experiences of residents. Inspection reports from 2019 are available on the HIQA website, www.hiqa.ie.

During the year, many providers continued to improve their services and to enhance the quality of life of residents, while also achieving higher regulatory compliance. Other providers are incrementally improving their services and are on a positive trajectory towards achieving high levels of compliance with the regulations. However, we found that some providers in a range of centres did not meet key regulations, and they were required to take action to improve the lived experience of residents. Inspectors held providers to account where care and support fell short of what residents and their families should expect of a quality service.

Of particular concern during 2019 were limitations on the human rights of many residents living in congregated or campus-based settings. These are centres where more than 10 people live in the same building or in a group of buildings which are located together on a campus. These institutions are often separated from the local community with all services, including social activities, provided on the grounds. In 2019, providers of many of these centres did not consistently achieve the same levels of compliance in key regulations as providers of community-based centres did. Providers of congregated settings were challenged in their ability to provide a dependable service that promoted and protected the rights, safety and quality of life of residents.

An important aspect of our work each year is listening to and communicating with residents and their families. During inspections in 2019, inspectors spoke with residents about the quality and safety of their services. Many residents had very positive things to say about the services they were receiving and about the staff in those services. However, many residents in congregated settings frequently told inspectors that they were not satisfied with the services being provided to them and the choices available to them in their daily lives.

Our previous overview reports have highlighted the importance of strong governance and management systems and the positive impact that this has on the overall experience of residents. Our 2019 inspections continued to reinforce that finding. During the year, centres with high levels of compliance against the governance and management regulations tended to be the same centres where residents were safe from the risk of abuse and where their human rights were better protected.

While this report presents the findings from the work of inspectors of social services in designated centres for people with disabilities during 2019, it is acknowledged that there are many new challenges for providers in 2020. These challenges include how to continue to promote the human rights of people of people with disabilities in a time of unprecedented public health concerns and restrictions. We will continue to use our regulatory powers to improve supports for people with disabilities in designated centres, so that they can live a good quality of life and be part of their local communities to the greatest extent possible.



Finbarr Colfer

Deputy Chief Inspector of Social Services (Disability)

Health Information and Quality Authority

Chapter 1. Listening to the views of residents

1.1. Introduction to engaging with residents during inspections

Inspectors may not always be able to communicate with some residents due to the nature of their disability, or residents may choose not to engage with them, as is their choice. Nonetheless, inspectors make every effort to seek residents' views on different aspects of day-to-day life in the centre during inspection. This will either be through:

- communicating directly with residents
- communicating with residents through:
 - an advocate,
 - family member
 - or member of staff
- meeting groups of residents
- observing what day-to-day life is for residents or
- gathering written feedback using questionnaires.

Inspectors are very aware that a designated centre is a person's home and are therefore aware of the importance of residents' privacy during an inspection. Inspectors take measures to address any concerns that residents may have, including minimising disruption to the residents' normal routine wherever possible.

In 2019, around 70% of inspections carried out were unannounced while 30% were announced. Unannounced inspections are necessary to ensure inspectors get an accurate picture of normal, daily life in a centre. Where inspections are announced, the inspector will ask the registered provider in advance of the inspection to inform them about any specific needs that residents may have. In some cases, this has involved meeting with a resident in a different location so that they can meet the inspector in person prior to the inspection.

Information posters with details of the upcoming inspection are sent to designated centres before announced inspections take place. Providers are asked to display these posters prominently in the centre to inform 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 or their advocates about their experiences of the service are also sent out to centres in advance of announced inspections. This allows residents and relatives to give their feedback. Following consultation with family

members and residents, HIQA revised the questionnaire for residents in 2018. The questionnaire is also available to download on www.hiqa.ie and can be completed by residents or their representatives outside of the inspection process and returned directly to HIQA.

1.2. Capturing residents' voices in the inspection report

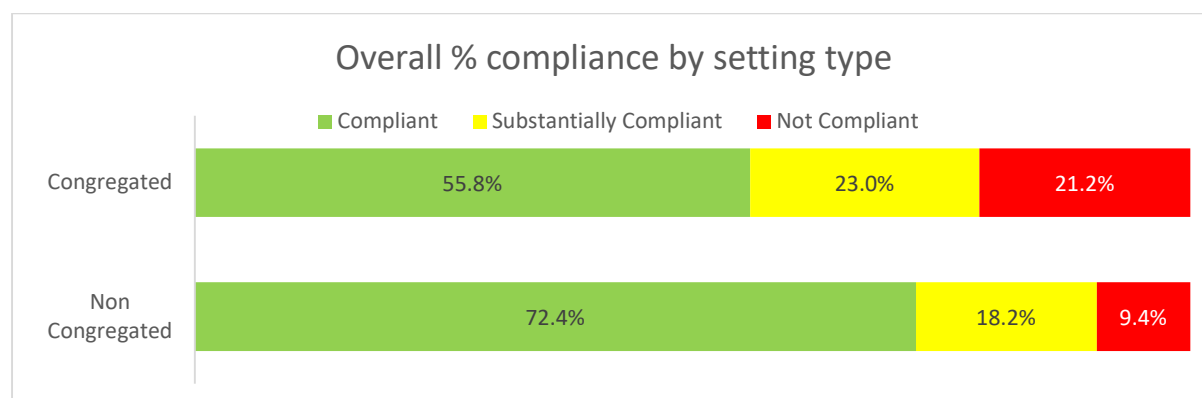
All of our inspection reports include a section called 'What residents told us and what inspectors observed'. In this section, inspectors outline what residents told them on the day of inspection or through the questionnaire about what it is like to live in their home. As some people are not in a position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

On every inspection, inspectors aim to meet with the residents, while respecting everyone's individual preferences, rights and needs. Over the course of 2019, inspectors met with a large number of residents in designated centres throughout Ireland, spending time listening to residents and observing life for them in general during inspections.

Throughout 2019, HIQA found that residents who had more freedom in exercising their human rights lived in centres with higher levels of compliance with the regulations. For example, residents who had moved from congregated settings to the community told inspectors about their new way of life and new levels of freedom.

Echoing these sentiments from residents, inspections found that centres in the community had higher levels of regulatory compliance than those in congregated settings. Figure 1 below shows that overall non-compliance levels in congregated settings were over twice that of non-congregated centres (centres in the community) during inspections in 2019.

Figure 1. Comparison of overall compliance levels in congregated and non-congregated residential disability settings in 2019



1.3. What residents told us on inspection in 2019

Most residents told inspectors that they were happy in their homes and that they felt safe. While most residents felt they had choice and control over their daily activities, and said they felt supported by staff in line with their needs and wishes, others felt they had less control and choice. A number of residents emphasised how important their families were to them and how they enjoyed family members visiting their home. Those residents told inspectors about the support they received from staff to facilitate this.

In well-managed centres, residents enjoyed telling inspectors about how they liked to spend their time and about the activities or people that were particularly important to them. The list of hobbies and interests that residents had were many and varied. These often included going on holidays or outings, swimming, dance exercise classes, bowling, knitting clubs, meeting friends and volunteering in the local community. They described how staff supported them to spend their time engaging in activities, further education and training of their choice. Others said they really enjoyed their jobs and were proud of the work they did.

However, in some congregated settings, the residents' day was primarily focused on campus-based activities. These activities were often further limited by staff shortages. For example, inspectors saw situations where external activities had to be delayed or cancelled because transport had to be shared between a large number of residents. A number of residents living in congregated settings expressed their frustration to inspectors about the length of time being taken for them to move to community-based services. Worryingly, some residents said that they had stopped engaging in advocacy meetings to support their plans to transition to the community, as they felt progress was not being made.

Residents in both congregated settings and in community houses often told inspectors about the support they received from staff. They spoke about the importance of having familiar staff support them. This allowed them to be comfortable speaking to staff about anything that was affecting them. Some residents thought that things could be better if there were more staff members on duty in their centre.

Many residents living in the community highlighted that they had developed independent living skills or enjoyed being supported to engage in tasks in their homes. These included cooking, cleaning and laundry tasks. They assisted staff with planning and accompanied staff with the weekly food shopping. This resulted in residents having a sense of ownership and control in their own home and of being active participants in the day-to-day operations of their home.

This was in contrast with many congregated settings, where inspectors found that residents were not actively being supported to engage in the running of their own home or developing independent living skills, such as doing their own laundry or preparing their own meals. This was primarily due to the design of the buildings where they lived, which tended to have centralised kitchen facilities or laundry facilities.

While the majority of residents told inspectors that they were happy in their homes, some residents expressed dissatisfaction with the size of their bedrooms or communicated other issues in relation to the condition of the premises. For example, some residents told inspectors about how important their bedrooms were to them and showed inspectors how they had personalised their rooms to represent their achievements and interests.

However, in some centres, particularly congregated settings, some residents did not have their own bedrooms and told inspectors about the difficulties with sharing their rooms with other residents. Some said they would prefer their own rooms. Other residents told inspectors that they did not like living with the people in their home and in some cases, were afraid or felt uncomfortable or unsafe in their home.

The views expressed by residents themselves shows that the type of centre that residents live in, and the supports that are available to them, can either positively or negatively impact directly on their ability to exercise their human rights and live a good standard of life.

1.4. The impact of compliance with regulations on residents' lived experiences and human rights

Wherever providers comply with the regulations, there is evidence of positive outcomes for residents — this means that residents are living in safer environments and are able to enjoy more meaningful lives of their choosing in their local communities. Where a provider fails to meet the minimum requirements of the regulations, this has a direct negative impact on residents, and it may increase the risks of negative outcomes to residents' quality of life or their safety.

During 2019 inspections, residents provided feedback on their services and how their human rights were being supported. Residents often had positive things to say about these services. However, residents also highlighted aspects of their services which needed to be improved and where they believed their voices were not being adequately listened to. Centres which were found to have higher levels of compliance with the regulations tended to be those same centres where residents gave more positive feedback about how they saw their rights being protected.

Regulatory activities in 2019 show how providers of well-managed centres ensure the active promotion and protection of the rights of people with disabilities living in residential centres. These rights are enshrined in the UN Convention on the Rights of Persons with Disabilities (UNCRPD). The Irish government formally ratified the Convention in March 2018, and it entered into force from 19 April 2018.³ Therefore, 2019 was the first full year in which Ireland was obliged under international law to abide by the legal obligations as set out in the Convention. The general principles underpinning the Convention include:

- respect for the dignity, autonomy and independence of people with disabilities
- full participation in society
- recognition and respect of people with disabilities as part of human diversity
- freedom to make one's own choices
- non-discrimination and equality of opportunity and
- respect for the evolving capacities of children with disabilities.

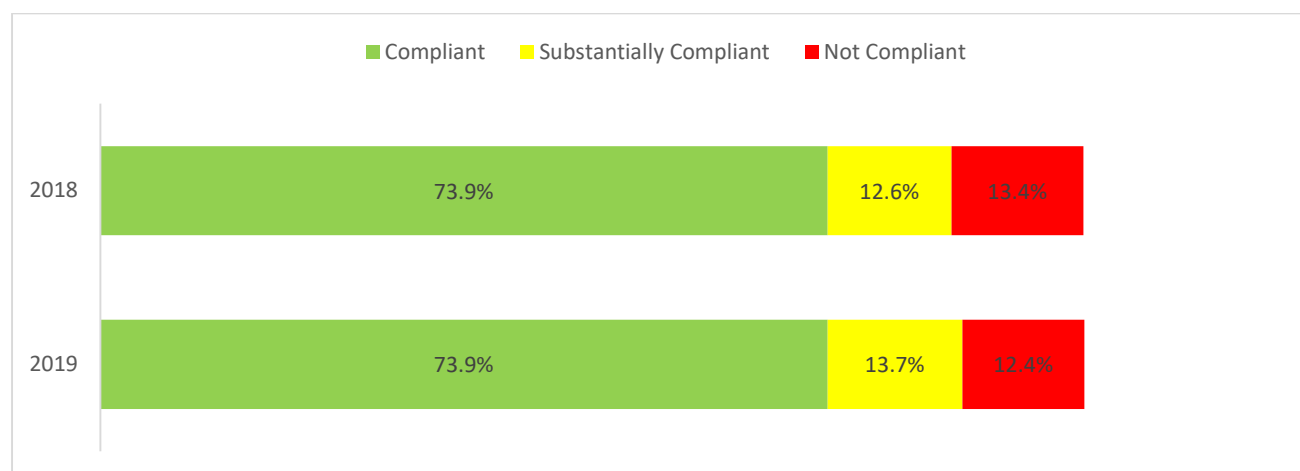
Monitoring activities in 2019 demonstrated the important links between:

- good levels of compliance with the minimum regulations
- the governance and leadership arrangements in place in the designated centres and
- the residents' experience of how their human rights were or were not protected and upheld.

During the 2019 inspections, it was found that a number of key areas continued to improve (see Chapter 2), with the exception of congregated settings where, overall, there were higher levels of non-compliance with the regulations. Non-compliance levels in congregated settings were noticeably higher than in community-based houses in relation to Regulation 9 which sets out the requirements in relation to residents' rights. Throughout this report, a comparison with compliance levels between 2019 and the previous year has been provided. In relation to residents' rights, inspectors did not find significant further improvements in compliance levels during 2019 (see Figure 2).

³ For further reading, see <http://nda.ie/Disability-overview/Legislation/UN-Convention-on-the-Rights-of-Persons-with-Disabilities.html>.

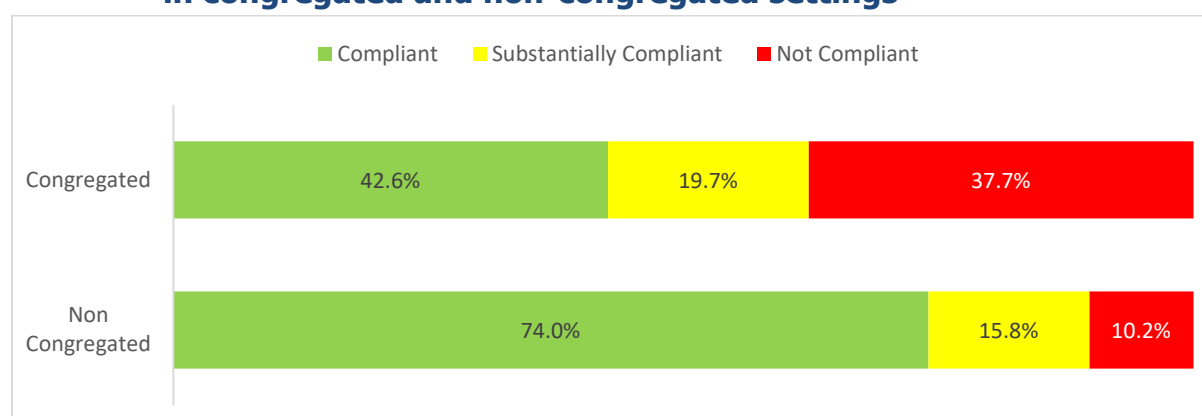
Figure 2. Comparison of overall compliance with Regulation 9: Residents' Rights between 2018 and 2019



During 2019, residents who lived in centres where there were higher levels of compliance told us about how their lives had improved. They gave examples of some of these improvements, and some residents attributed these improvements to the impact of regulation by the Chief Inspector. In these centres, residents told us that they had more freedom to choose who they lived with and to choose how they spent their time.

Having one's own key to their home was frequently referred to as bringing a sense of joy and independence to residents. Residents in these centres talked about the ways in which they were consulted and how this allowed them to become more involved in the running of their homes. Figure 3 demonstrates the significant difference in compliance levels between congregated and non-congregated settings in 2019 under Regulation 9 on residents' rights.

Figure 3. Comparison of compliance with Regulation 9: Residents' Rights in congregated and non-congregated settings



Monitoring in 2019 shows that congregated settings had lower levels of overall compliance with regulations when compared community based centres. Inspectors

found that most residents who lived in congregated settings did not have the same supports in place to help them exercise and enjoy their human rights.

Many residents in congregated centres did not choose who they lived with or who they shared their room with, and they often received support which was tailored to a larger group of residents rather than to their individual needs. There was a notable difference in how residents in these settings could become involved in the running of their homes, and this was reflected in what residents told inspectors.

1.5. Engaging with residents outside of the inspection process

At all times, the Chief Inspector welcomes information or feedback about residents' experiences of living in a designated centre or about the inspection process. Since the regulation of designated centres for people with disabilities began, the Chief Inspector has taken a number of steps to engage proactively with residents and national advocacy bodies.

During 2019, at the invitation of residents themselves, inspectors attended 18 residents' group meetings across the country. In total, 178 residents attended these sessions, providing valuable insights into their experience of inspections and of living in residential services.

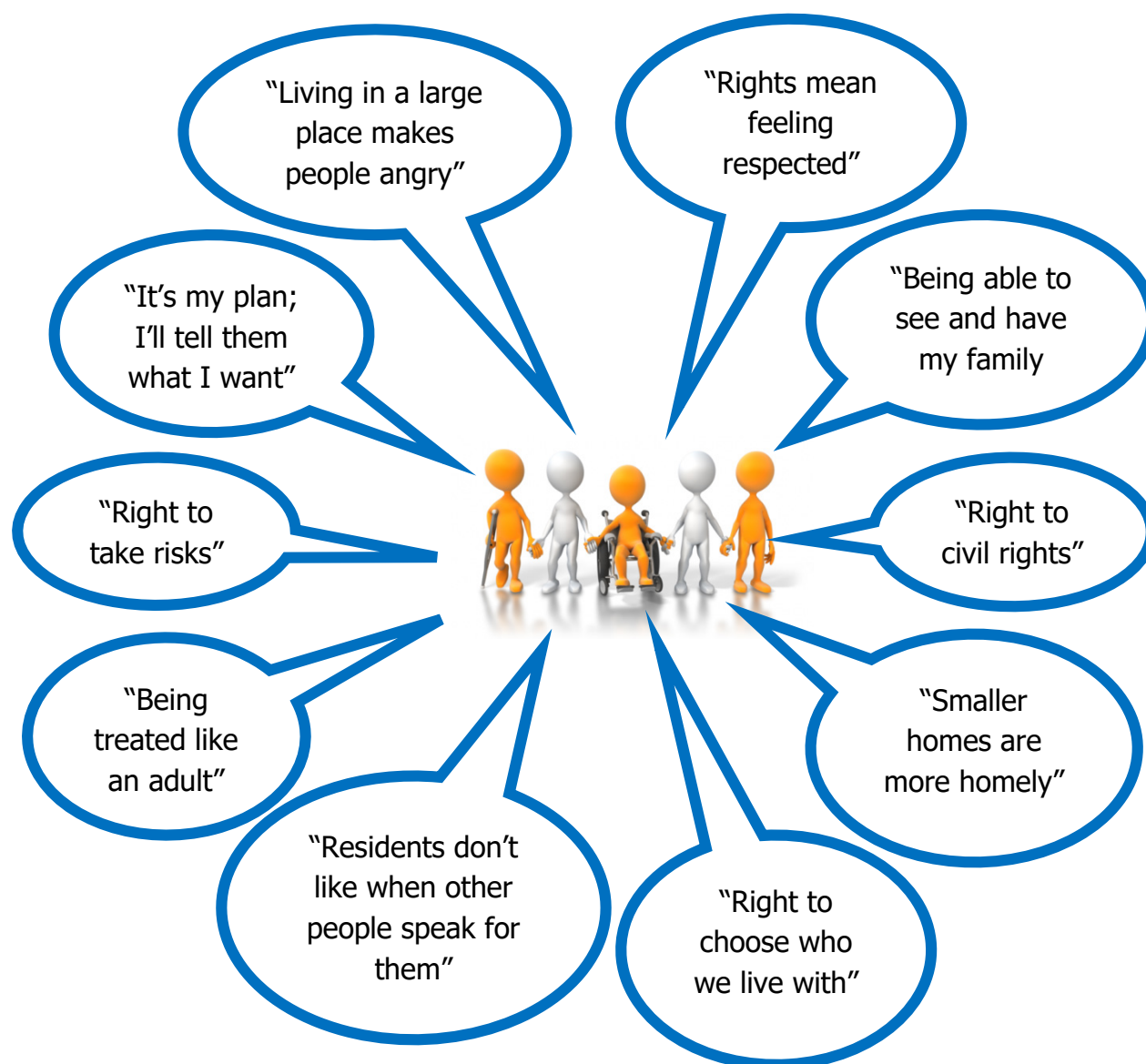
At these meetings, inspectors were able to discuss with residents their experience of regulation and how this has impacted on their quality of life and experiences living in regulated centres. Being able to meet with residents outside of the inspection process allowed inspectors to gain a greater understanding of the reality of their lives and what they felt should be prioritised during inspections.

1.6. What we heard during group meetings of residents

Overall, residents in the group meetings said that they welcomed regulation, with some residents saying having somebody to check up on services ensured standards were in place, as feeling safe was very important to them. In a number of group meetings, residents felt that there should be more accessible information available to them about the work of HIQA and said they would like visual aids such as video clips, a photo of the inspector and easier-to-read documents.

Figure 4 shows a sample of residents' views collected during these group meetings.

Figure 4. Sample of residents' views on matters that are important to them and which were collected during group meetings



Residents in a number of different group meetings gave examples of where they felt that regulation had made a positive impact on their lives. There was a strong emphasis from residents about how they wanted to be involved in their home and the importance of having their voice heard by staff and by inspectors.

During these group meetings, one of the clearest messages from former residents of campus-based settings was that life is much better in the community. Residents spoke about the importance of getting to know people in their local community and participating in events locally.

Some residents said that they are now more involved in the decisions in their home and that they were not involved when they lived in a large institution. Living in a smaller home with their own room was very important to residents. Some residents said that they believed that was it not for regulation of residential centres they would never have moved out of congregated settings.

1.7. Next steps in hearing from residents

The Chief Inspector is using the information provided by residents in these group meetings to improve or prioritise areas of the inspection process. An action plan is being developed to inform future inspection processes. The views of residents and the action plan will be published in 2020.

Chapter 2. Analysis of regulatory compliance in congregated versus community settings

2.1. Introduction

By the end of 2019, there were 1,268 designated centres with 9,064 people with disabilities living in them. Of the 9,064 residential places registered by the end of 2019, nearly one in three (32% or 2,914 places) continued to be located in congregated settings. Of these, 2,368 residents were living in campus-based settings and 546 residents were living in stand-alone congregated settings for 10 or more people. See Chapter 4 for further detailed information.

This section of the report presents information about compliance levels in 2019 against a number of key regulations. The regulations outlined in this chapter were chosen because they are a good measure of the overall quality and safety of care and give us a picture of what it is like for residents in centres. The data presented below demonstrates the inequalities in the quality of care and support that continues to be experienced by residents living in congregated settings compared to their peers who live in smaller, community-based settings.

2.2. Governance and management

Good governance and management continue to be a fundamental cornerstone in the successful delivery of a good quality and safe service to residents living in designated centres, regardless of the setting. Effective governance and management systems support providers to understand and analyse the quality of their own services. They enable them to take timely action to ensure that any deficiencies in the quality and safety of the care and support or in the day-to-day running of the centre are addressed and quickly resolved. An example of improved governance during 2019 is illustrated here:

The management structure and staffing levels in the centre have also been restructured. The role of the person in charge had been changed and the person in charge now has responsibility for two designated centres [previously the person in charge had responsibility for a large number of centres]. This significantly increased the amount of time the person in charge spent at the centre and ensured that audits, reviews and improvements were taking place.

Extract from inspection report in 2019

Figure 5 shows compliance findings against Regulation 23 on governance and management in 2018 and 2019. During 2019, inspectors consistently found that providers' governance arrangements in many congregated settings were unsatisfactory (see Figure 6). This was particularly evident in settings with a higher number of buildings or units or a high number of residents. In many of these settings, inspectors often found that oversight by the provider was severely impacted by the failure of its internal oversight systems, including the quality and effectiveness of its audit programmes.

In essence, where there were poor findings, providers did not have a clear picture about what was happening in their services and were routinely failing to adequately identify deficiencies in the quality and safety of their services. In some instances, where audits had identified areas for improvement, inspectors found that recommendations had not been subject to regular monitoring or review to ensure that they were being appropriately implemented.

Figure 5. Comparison of 2018 and 2019 in relation to compliance with Regulation 23: Governance and Management

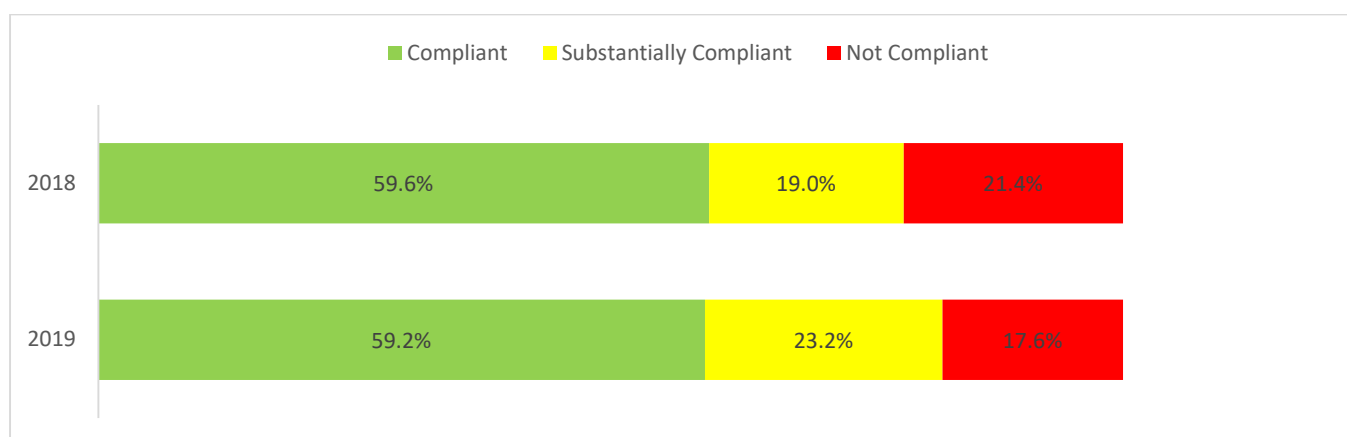
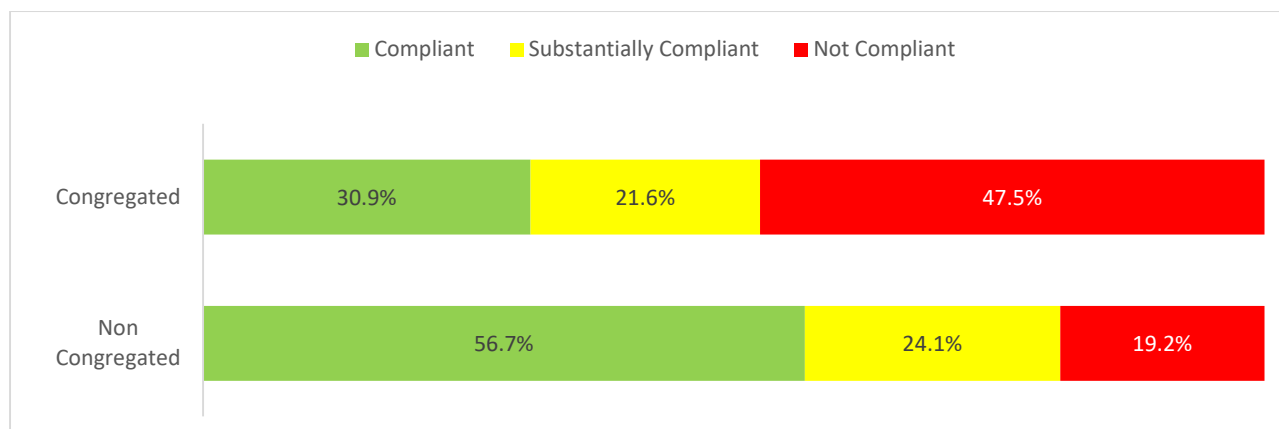


Figure 6. Compliance with Regulation 23: Governance and Management in community settings and congregated settings



Although improvement continued to be required in community-based centres, inspectors found that most of these centres — in comparison to congregated settings — were well-managed with clear, accountable management structures in place. They tended to be smaller in size, both in premises and in the number of residents living in the centre. Management was found to be either based at the centre or regularly present in the centre, therefore ensuring clear oversight of care practices and the day-to-day operations of the centre.

2.3. Safeguarding

The safeguarding measures that a provider puts in place to prevent and protect residents from abuse are a core requirement of a safe and quality service. In the event that a resident experiences harm or abuse, how a provider responds is a key consideration in determining the level of compliance against the safeguarding regulations. The provider's response includes putting measures in place to improve their safeguarding arrangements, monitoring the effectiveness of these arrangements, and consistently reviewing them.

In December 2019, HIQA and the Mental Health Commission jointly published the *National Standards for Adult Safeguarding*.⁴ These standards aim to make a significant contribution to improving safeguarding practices in Ireland, particularly in designated centres. All providers and members of staff are urged to familiarise themselves with the safeguarding standards, which are available on the websites of both organisations.

All adults have the right to be safe and to live a life free from harm. Safeguarding means putting measures in place to promote and protect people's human rights and their health and wellbeing, and empowering people to protect themselves. It is fundamental to high-quality health and social care.

National Standards for Adult Safeguarding, 2019

However, the absence of specific safeguarding legislation in Ireland remains a significant concern to HIQA. Despite the absence of a clear legal safeguarding framework for vulnerable adults, Regulation 8⁵ of the care and support regulations requires the provider and the person in charge to ensure that there are suitable

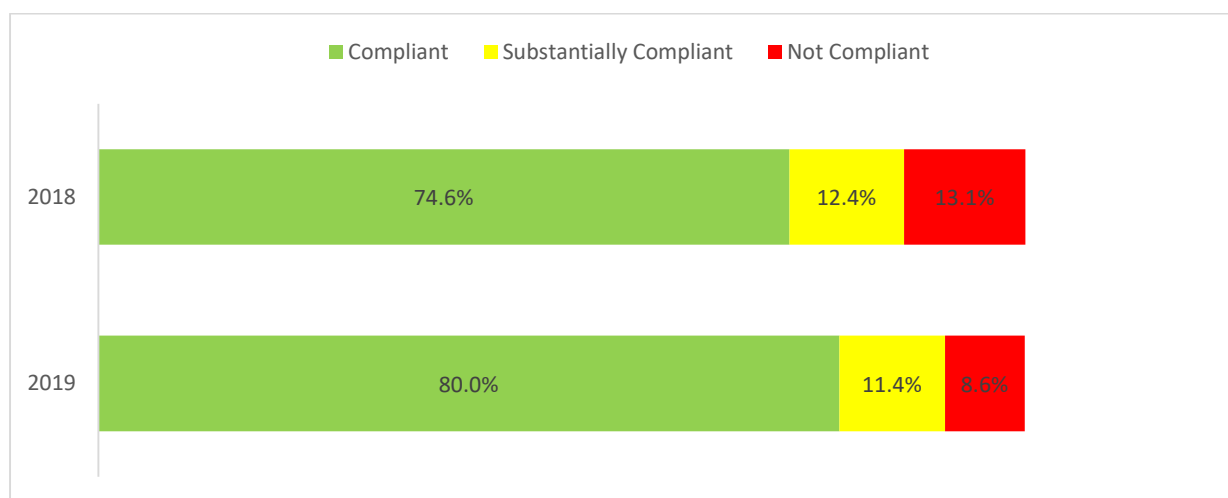
⁴ <https://www.hiqa.ie/reports-and-publications/standard/national-standards-adult-safeguarding>

⁵ Health Act 2007 (Care and Support of Residents in Designated Centres for Persons (Children and Adults) with Disabilities) Regulations, 2013.

safeguarding arrangements in place and that residents are protected from the risk of abuse.

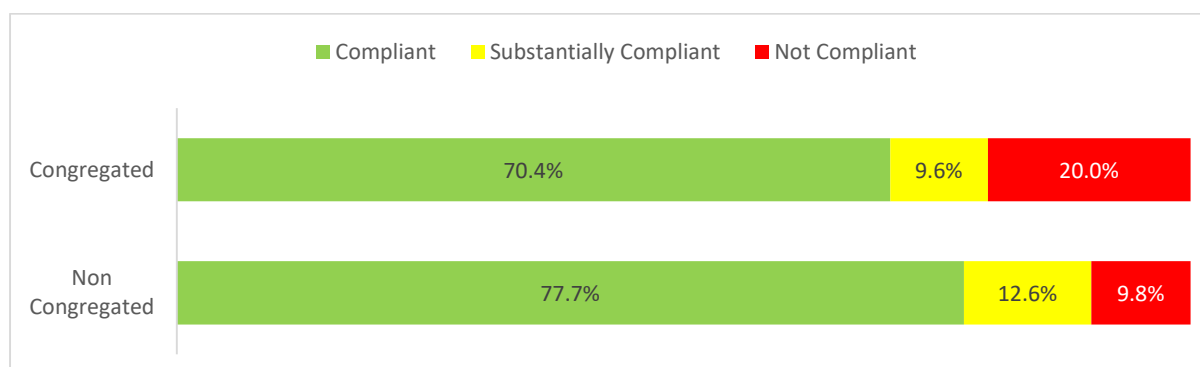
There has been a small improvement in compliance levels with this protection and safeguarding regulation since 2018 (see Figure 7). Inspectors found that providers who ensured good governance arrangements to oversee safeguarding — with a regular review and monitoring of those arrangements — were more effective in safeguarding vulnerable residents from the risk of abuse.

Figure 7. Comparison of overall compliance against Regulation 8: Protection, in 2018 and 2019



However, the level of non-compliance with safeguarding requirements in congregated settings was double that of community houses, as illustrated in the compliance findings in Figure 8.

Figure 8. Level of compliance with Regulation 8: Protection, in congregated settings and community-based settings



Where inspectors found good compliance with the regulations on protection, there was good evidence that the provider had clear safeguarding processes in place, had ensured staff were adequately trained in these safeguarding arrangements and were implementing those arrangements. Residents living in these centres were often more likely to tell inspectors how they have been empowered to protect themselves and that they felt confident about raising any future concerns they might have.

While safeguarding concerns still occurred in non-congregated (community) settings, providers in these settings tended to respond more rapidly and effectively to these concerns in order to safeguard residents compared to in congregated settings. For example, inspectors saw that where there had been issues of peer-to-peer altercations, some providers had taken effective action in relation to the compatibility of residents who were living together.

In other centres, there was good evidence that the provider was reviewing the effectiveness of its training to increase staff knowledge and skills in safeguarding. Other providers had actively increased their staffing levels or had made changes to the layout of their designated centres in order to reduce the impact and likelihood of safeguarding concerns or abuse. An example of failings seen by inspectors includes:

Compatibility issues between some residents had resulted in safeguarding concerns and an unacceptable level of risk of peer-to-peer assaults, social care activities were restricted due to staff shortages, and there was an over reliance on the use of relief staff which was impacting negatively on the continuity of care provided to the residents. As a result, there were unacceptable negative impacts on residents living on this campus.

Extract from inspection report in 2019

In one in five congregated settings (20%), inspectors found that residents continued to be at significant risk of abuse due to non-compliance with the basic requirements for safeguarding as set out in the regulations. In many of these centres, the providers' governance arrangements had failed to make sure that allegations of harm were being reported and investigated to a satisfactory level.

In some cases, staff were failing to recognise safeguarding incidents due to their frequency, suggesting that the culture of the centre was used to or had a higher tolerance for such events. In these centres, where safeguarding concerns had been reported, inspectors found that management had not ensured that effective plans had been put in place to mitigate these events.

Where safeguarding plans had been implemented by providers, these were not always subject to regular review to make sure they kept the residents safe. Whenever inspectors observed such incidents, or found evidence of them, providers were required to take immediate action to address any safeguarding concerns to ensure the ongoing safety of all residents in the centre.

2.4. Social care

Elements of many people's lives in society include: being able to choose where or who you live with; identifying your support needs and being in control of how these are met; being able to work or spend time with your friends or family; and being able to engage in a hobby. As citizens, people with disabilities who live in designated centres have the same rights⁶ as others in society in relation to living the life they choose and accessing the resources they require to do that.

Aspects of how providers demonstrate that they are ensuring that residents are supported to exercise these rights are found in Regulations 5 and 13 of the 2013 care and support regulations. These regulations require providers to put in place certain arrangements to meet the assessed needs of residents. This extract from a 2019 inspection report shows an example of how providers are meeting these regulations:

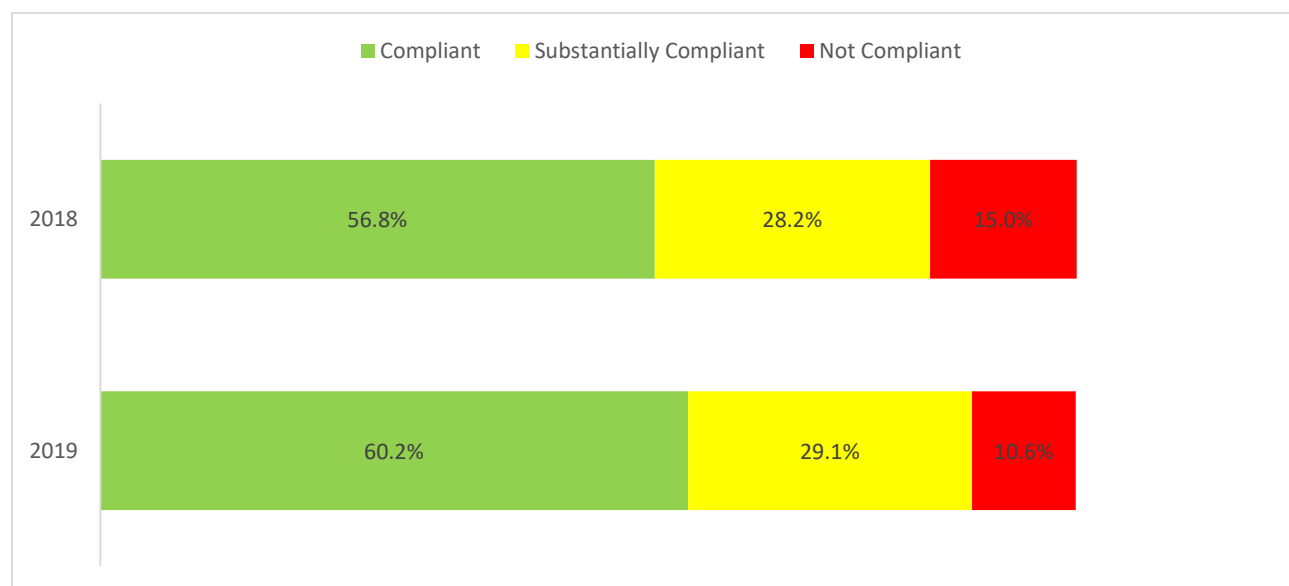
There was a strong emphasis placed on the residents' choices and their preferences were evident. Their social care needs were actively promoted and encouraged and they accessed numerous external activities such as the local walking club, cinema trips and their local communities. Residents had very busy lives and staff endeavoured to source new experiences and appropriate activities as often as possible.

Extract from inspection report in 2019

Figure 9 on the following page shows a comparison between 2018 and 2019 of compliance with Regulation 5: Individual Assessment and Personal Plan.

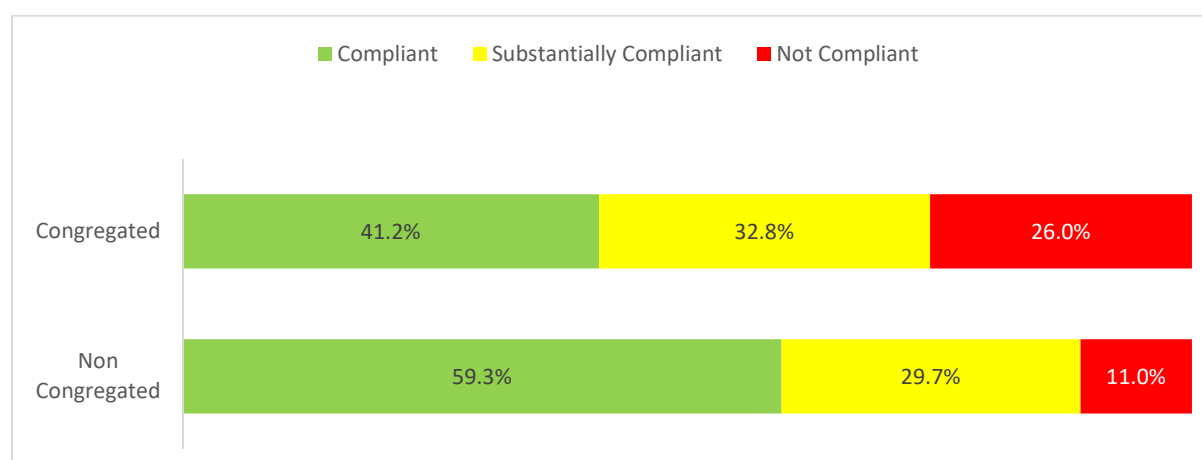
⁶ The United Nations Convention on the Rights of Persons with Disabilities and Optional Protocol <https://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>.

Figure 9. Comparison of 2018 and 2019 compliance with Regulation 5: Individual Assessment and Personal Plan



Overall, inspectors found that there continued to be improvements in compliance against this regulation compared to previous years. However, there was a higher level of non-compliance in congregated settings, which meant that residents in these settings had less access or support available to them to help them achieve the best possible degree of independence. In contrast, residents in community settings were more likely to experience better personal planning arrangements, with more choice, independence and control in their daily lives (illustrated in Figure 10); although improvements were still required in some of these settings.

Figure 10. Level of compliance with Regulation 5: Individualised assessment and personal plan



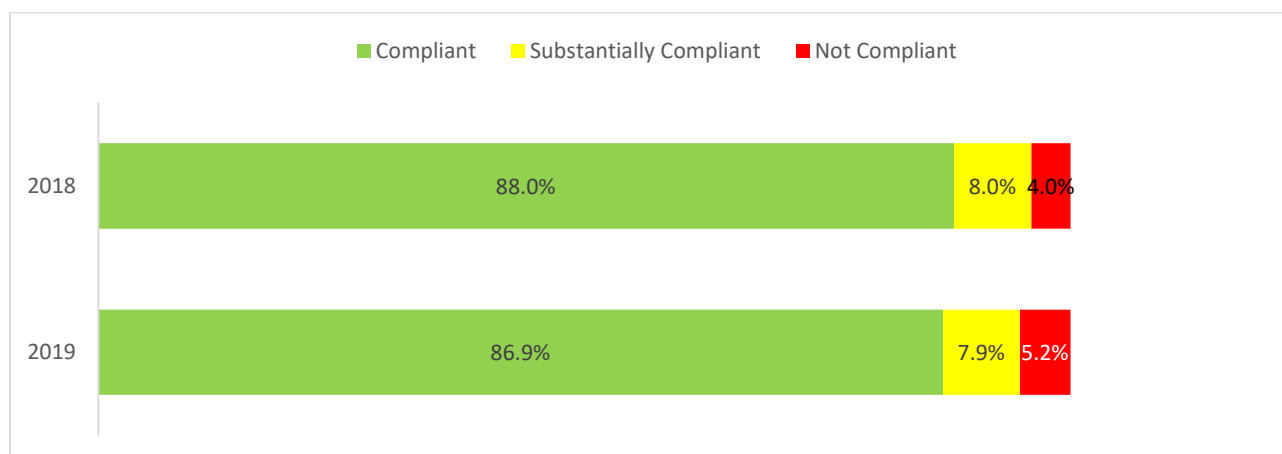
In relation to the congregated settings that had higher levels of non-compliance, inspectors continued to find that residents' support needs were not being adequately assessed. In these centres, clear personal support plans had not been put in place to

guide staff and make sure a consistent standard of quality care was being provided. In some instances, where plans had been developed, they were not being reviewed regularly to ensure that they continued to give guidance to staff on how to support residents appropriately.

In examples of good practice, inspectors reported that in centres with good levels of compliance, there were up-to-date comprehensive personal plans for residents, which were subject to frequent review to reflect the changing needs of residents. In addition, inspectors saw examples of where providers had taken initiatives to develop easy-to-read and accessible personal plans for residents. This ensured that residents and their representatives had a clearer understanding of how their needs would be met at the designated centre.

2.5. General welfare and development

Figure 11. Comparison of 2018 and 2019 overall compliance with Regulation 13: General welfare and development



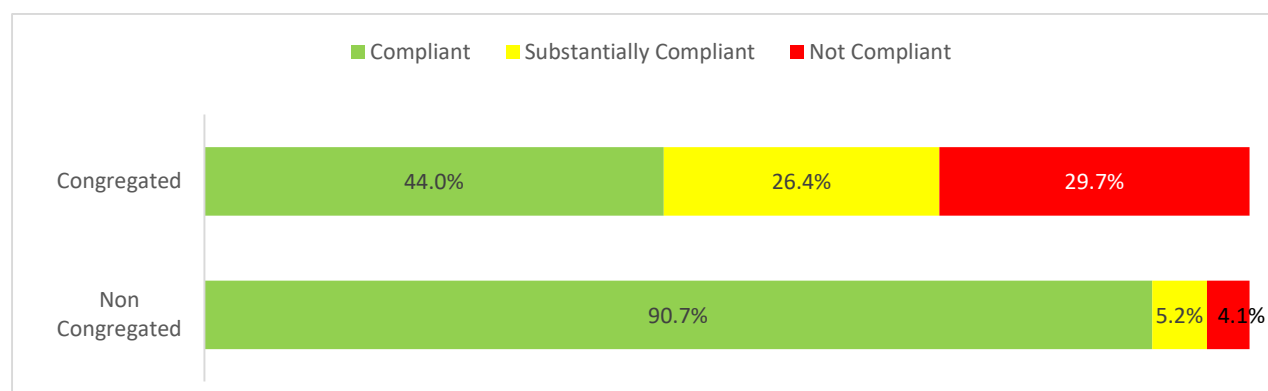
Overall, there was good compliance with Regulation 13, but with significant variation between congregated and community settings.

As shown in Figure 11, there was a slight deterioration in the overall level of compliance with Regulation 13 between 2018 and 2019. Inspectors found that residents living in congregated settings had significantly less opportunities to play an active part in their local community than those living in non-congregated settings (see Figure 12 on the following page). In congregated settings, opportunities to engage in activities were regularly impacted by the lack of availability of staff and suitable transport. On many occasions, staff numbers determined whether an activity would be based on the campus or in the wider community.

Inspectors were made aware of examples in congregated settings of staff taking residents for a drive outside of the campus, but residents not being able to leave the vehicle and participate in their local community because of inadequate numbers of

staff. Inspectors also found examples of activities for residents in congregated settings being restricted to the grounds of the congregated setting because of inadequate arrangements to meet the support needs of some residents. This meant that residents were frequently not being actively supported to achieve their personal goals or to engage as equal participants in their local communities.

Figure 12. Level of compliance with Regulation 11: General welfare and development



In contrast, inspectors found that residents in community settings were more likely to be supported to develop strong community links and become active members of their local community. Residents were being assisted to broaden their expectations of the activities they wished to experience. Inspectors specifically found that where residents had moved from a congregated setting into community living, they had increased opportunities to enjoy and participate in their communities. Residents were enthusiastic about the positive impact this transition had made on their lives, as illustrated in this extract from a 2019 inspection report:

The inspector found that the lives of residents have greatly improved since moving from the campus. Residents were now active members of their local communities with some residents volunteering in local charity shops, exploring employment opportunities and being supported to gain greater independence.

Extract from inspection report in 2019

2.6. Risk management

Providers are required to ensure that they have systems in place for the ongoing assessment and management of risks which could cause harm to residents. Effective management and oversight of risk in designated centres for people with disabilities

ensures that there is a good balance between safeguarding residents from harm and positive risk taking. In positive risk taking, a risk-averse culture is avoided and residents' abilities are recognised and they are encouraged to be independent, despite a degree of risk arising with such independence.

Overall compliance with the regulation on risk management improved between 2018 and 2019, as illustrated in Figure 13. However, in 2019, inspectors found that although risk management arrangements were in place in both congregated settings and community-based centres, compliance levels indicate that these were less effective in congregated settings (see Figure 14). This meant residents in congregated settings had higher risks in relation to their quality of life and human rights than those living in community settings.

Figure 13. Comparison of 2018 and 2019 overall compliance with Regulation 26: Risk management

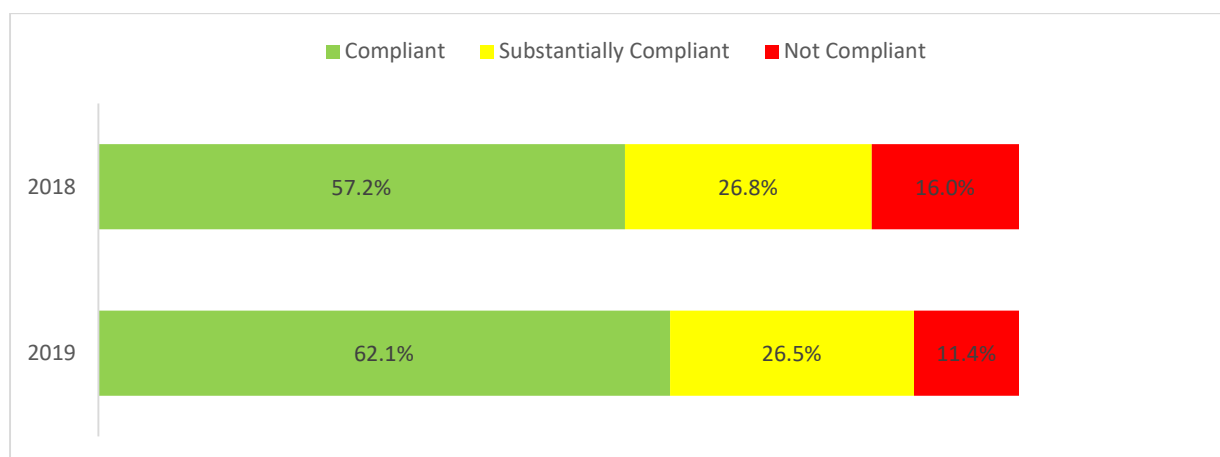
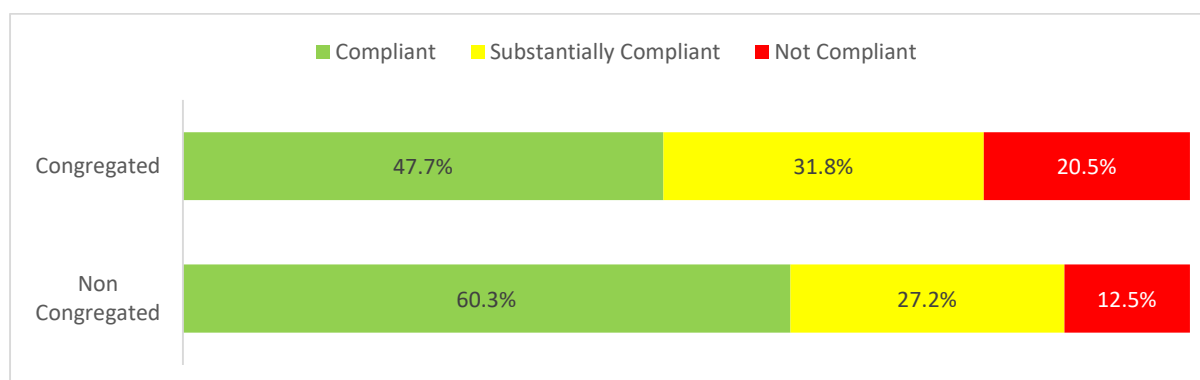


Figure 14. Level of compliance with Regulation 26: Risk management



While some risks can, with good planning, be effectively managed — such as the risk of fire in a centre — other risks are more transient and unpredictable. The capacity to recognise and respond to risk in a proportionate and timely way, which ensures that there are minimal restrictions on a resident's daily life, are key elements of a good risk management system. Any identified risks, whether these are individualised

or organisational, should be subject to regular scrutiny and review. This is to ensure that there is good awareness of relevant risks and that controls are in place to effectively minimise the risk.

Good governance was found in a variety of settings and ultimately meant that risks for residents were more readily identified and managed, resulting in them having less impact on residents' daily lives. In centres with good governance, most residents were being empowered through positive risk taking. This meant that residents were being supported to do things which carried more risk, were able to make more independent decisions and had more control and autonomy in their lives. An example of such an approach is shown in the following inspection findings:

Risk assessments were reviewed regularly and showed clear links to each resident's assessment and personal plan. Control measures showed consideration of the need to achieve balance between promoting residents' personal development and maintaining their safety.

Extract from inspection report in 2019

In contrast, although risk management arrangements were in place in congregated settings, these did not always reduce the impact of the risk on the residents' day-to-day lives. Inspectors often found that risk assessments were very generic and less person centred.

In some large congregated settings, there were still examples of risks being managed collectively. This approach had unintended consequences for many residents, limiting their freedom of movement and in some cases placing unnecessary restrictions on their lives. One example of this was a decision to lock access to a kitchen for all residents due to the risks posed to one particular resident in the centre.

Inspectors found that in some centres with poor compliance levels with risk management, even when risk management interventions had been developed, these were not always consistently implemented. This was often due to inadequate staffing arrangements or lack of staff knowledge of the control measures to be put in place or of the risk management plans in the centre. This was particularly a problem when agency staff were covering for regular staff and had not been properly briefed on risk management arrangements.

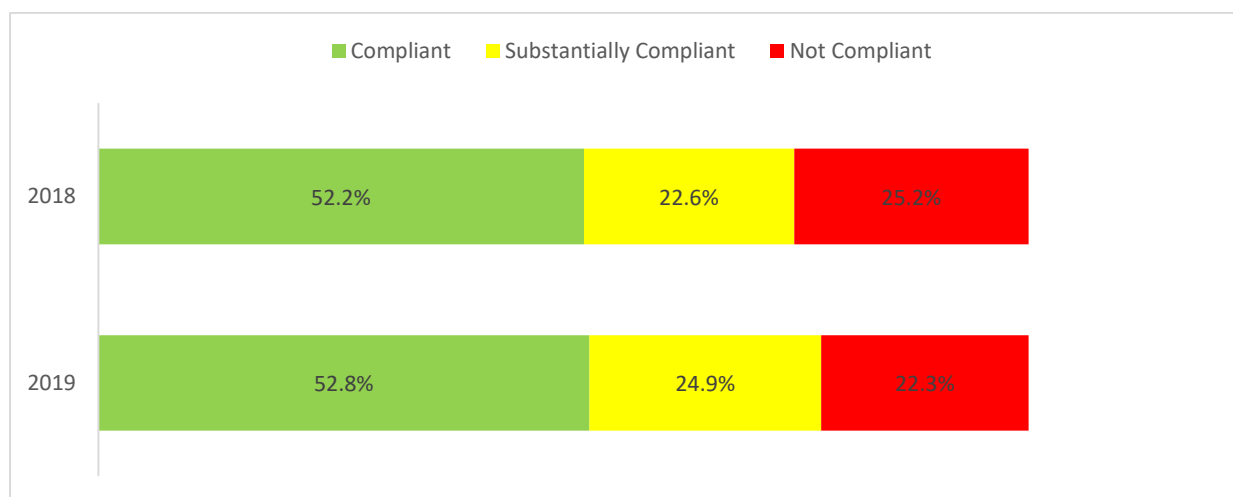
2.7. Fire safety

Providers must have suitable arrangements in place to manage the risk of fire and ensure residents are safe in their homes at all times. Where inspectors identified issues with fire compliance, providers were requested to have their own fire expert review fire precautions and identify any shortcomings that needed to be addressed. The level of compliance in both congregated and non-congregated settings both require improvement and focus from providers (see Figures 15 and 16). The following extract shows one example where significant improvement was required:

The centre had no fire containment measures in any area and had no plans for the completion of works to address this failure.... The inspectors found that there was only one fire extinguisher available in each of the three houses and none available within each of the ten apartments....

Extract from inspection report in 2019

Figure 15. Comparison of 2018 and 2019 compliance with Regulation 28: Fire precautions

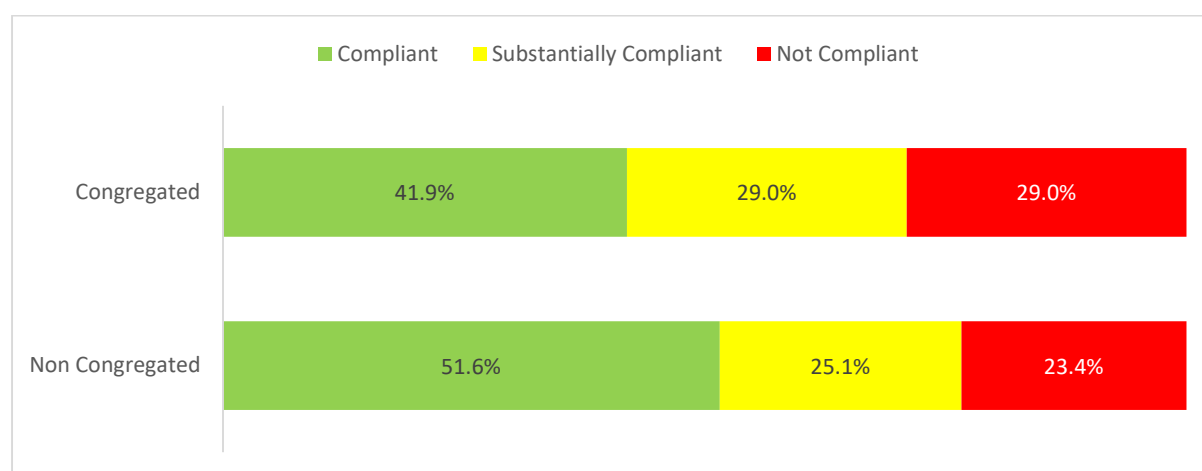


As discussed in Chapter 6, the Chief Inspector may attach additional conditions to the registration of a designated centre. These conditions may require the provider of a service to make time-bound improvements to centres, in order to fully comply with the Health Act 2007 (as amended) and the regulations. In 2019, 41 centres had a condition attached to their registration requiring them to improve fire safety measures in the centre; for example, where providers had insufficient arrangements in place for detecting and containing a fire or for safely evacuating the centre.

In general, inspectors found that fire safety measures and precautions in some larger congregated settings had a long way to go to meet the requirements of the regulations. In some instances, inspectors found that evacuation plans were not being kept up to date and did not provide sufficient guidance to staff in the safe and timely evacuation of the centre.

In other examples of poor compliance, although regular fire drills were being conducted, these were not always conducted at high-risk times, such as when there were minimum staffing levels in place, in order to test their effectiveness.

Figure 16. Level of compliance with Regulation 28: Fire precautions



Inspectors also found evidence that fire evacuation plans in some centres were not subject to regular review to ensure that they highlighted actions to be taken by staff in the event that residents refused to evacuate the centre during simulated fire drills or in genuine emergencies. This meant that providers could not demonstrate that, in the event of an emergency, they could safely evacuate all residents from the designated centre, thereby placing these residents at greater risk.

2.8. Premises

During 2019, little progress was made with improving the overall compliance rate with the regulation on premises (see Figure 17). The high level of non-compliance in congregated settings (Figure 18) continues to be of significant concern, despite some improvements. Providers must ensure that the living environment is well maintained and laid out to meet the needs of the residents.

Residents living in smaller, purpose-built or community houses had much better living conditions. In those centres, most residents had their own bedrooms and there was ample space both indoors and in the surrounding grounds for the residents and their visitors.

The following inspection report extracts highlight areas for improvement of the physical premises in congregated settings:

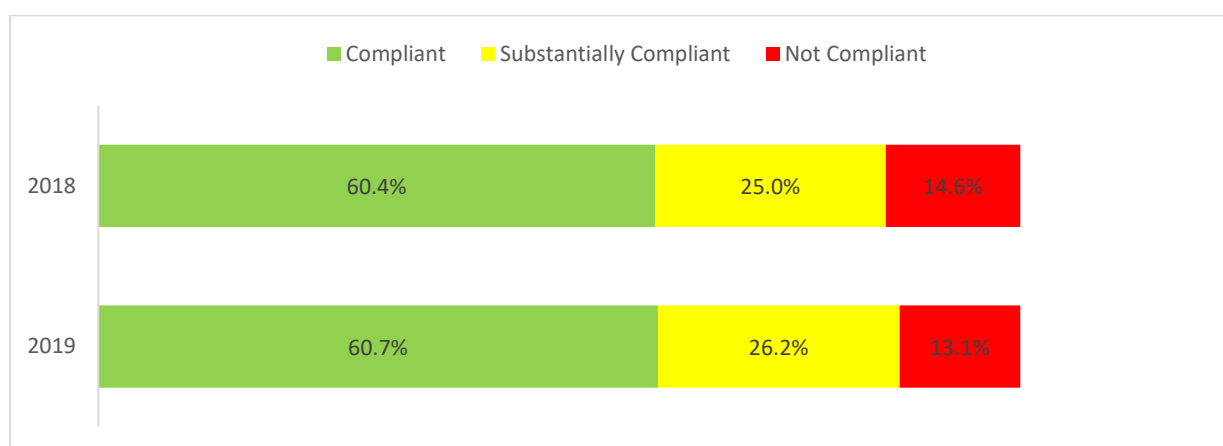
The centre was dark and not particularly homely in appearance. Despite efforts to personalise bedrooms with murals and personalised pictures, the centre's layout, design and operation was observed to be institutional, bleak and in need of decoration and maintenance in some parts.

Extract from inspection report in 2019

[There were] long dark corridors, locked doors [and] a high footfall of support and ancillary staff... many residents with incompatible assessed support needs were observed to be living together.

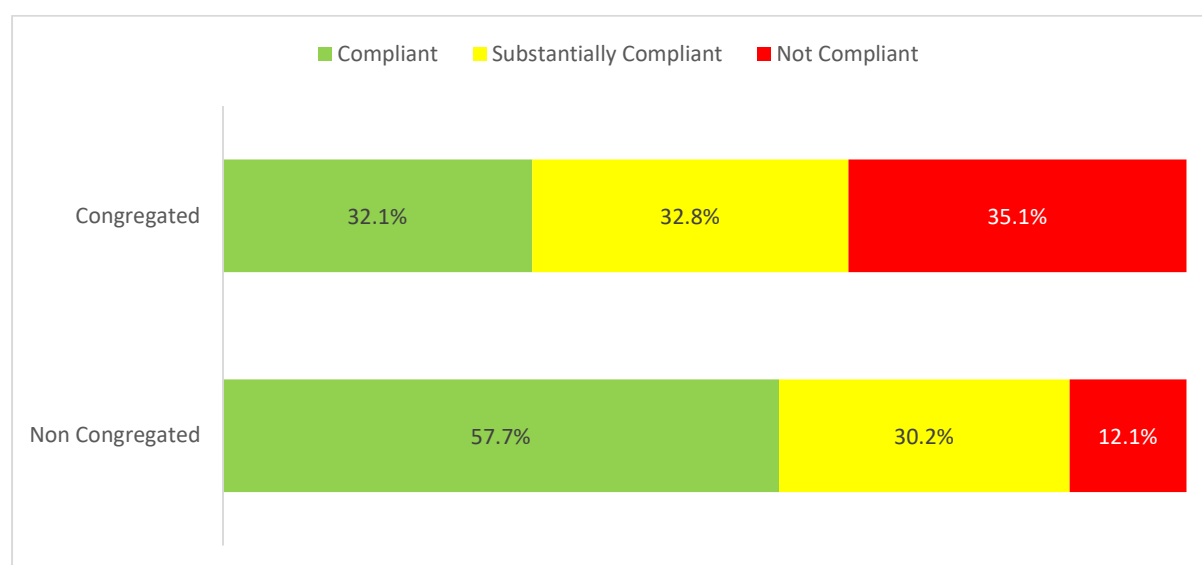
Extract from inspection report in 2019

Figure 17. Comparison of 2018 and 2019 overall compliance with Regulation 17: Premises



While many providers had endeavoured to create more homely environments in larger institutional buildings, progress was sometimes hindered by very poor building layout. In some centres, residents continued to share bedrooms or lived in hospital-type bays or dormitories. Residents had limited access — or often no access — to private space, kitchens or laundry facilities.

Figure 18. Level of compliance with Regulation 17: Premises



Although residents consistently told inspectors that they were happy with the centres they lived in, inspectors found that many congregated settings were in a poor state of repair. These premises were often unable to meet residents' assessed needs. Inspectors saw examples of where residents had limited or restricted mobility and were living in homes that had upstairs bedrooms but no lifts.

While measures had been implemented in some congregated settings to promote privacy for residents — for example, by installing privacy curtains around beds in shared rooms — these were only temporary solutions and themselves institutional in nature. Life for residents who continued to live in these old, dark institutional settings was often in stark contrast to the experiences of residents who had moved on to or lived in more modern designated centres in the community.

Chapter 3. A focus on human rights in the use of restrictive practices

3.1. Introduction to thematic inspections of restrictive practices

People have the right to live as independently as possible without unnecessary restriction. This can be achieved by both providers of designated centres for people with disabilities and staff proactively reducing and or eliminating restrictive practices in these centres.

In 2019, the Chief Inspector developed and commenced a 'thematic programme of inspection' to promote a human-rights based approach to the use of restrictive practices in designated centres for people with disabilities, with a view to minimising and eliminating their use. During thematic inspections, inspectors look for evidence that people's fundamental human rights are being upheld. They also look at whether their voices are heard, and whether the provider is ensuring that they are free to live in line with their choices and preferences.

This thematic programme was developed following extensive consultation with residents' representative organisations, providers' representative organisations and other informed and interested parties, such as health and social care professional bodies and people with an expertise in human rights.

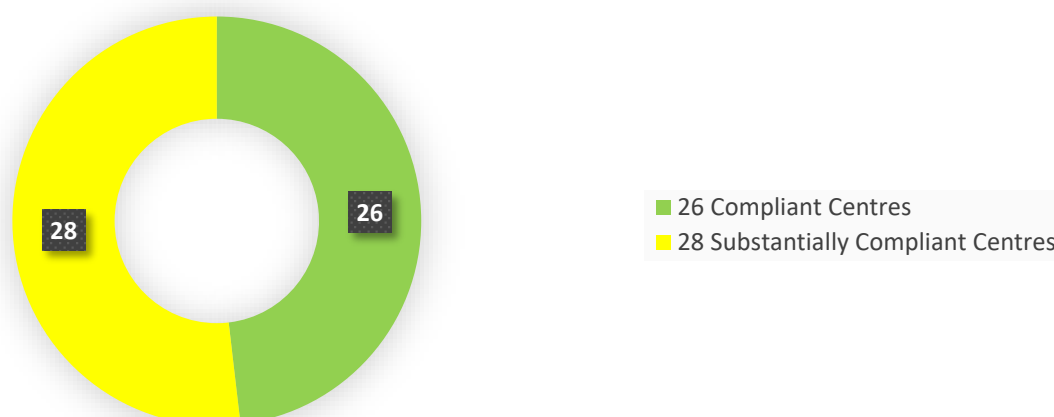
The programme focuses on assessing physical and environmental restraint, as well as other forms of restrictive practices (other than chemical restraint). It assesses performance against relevant national standards, rather than regulations, to promote quality improvement across services and to improve the quality of life of residents.

Further information on the thematic programme on restrictive practice can be found on www.higa.ie. See the *Guidance on promoting a care environment that is free from restrictive practice: Disability Services* at <https://www.higa.ie/reports-and-publications/guide/guidance-restrictive-practice-dcd>.

3.2. Findings of thematic inspections of restrictive practices

Inspectors completed 54 restrictive practice thematic inspections in disability residential services by the end of 2019. These inspections of 54 centres found that 26 centres were compliant and 28 were substantially compliant with the relevant national standards (Figure 19).

Figure 19. Thematic inspection compliance breakdown in 2019



Similar to risk-based inspections (see Chapter 4), these inspections found that effective governance and leadership arrangements were essential in making sure restrictive practices, where they were in use, were being implemented in line with relevant legislation and underpinned by good human rights-based principles.

In addition, many of these services had introduced strategies to continually review, reduce and (where possible) eliminate the use of restrictive practices. This in turn was found to be grounded by good quality staff training and education which directly influenced a culture of reducing the use of restrictive practices.

For example, in these centres there was evidence of:

- clearly recognising physical and environmental restraints
- identifying and eliminating 'custom and practice' approaches, including the removal of historical reasons for using restrictive practices, such as limited staffing, lack of training and lack of understanding of behavioural cues and triggers
- using consent forms — starting a conversation with residents on why and when restrictive practice may need to be used therapeutically
- deploying creative models of independent living, resulting in a significant reduction in the need for restrictive practices.

However, some providers continued to be challenged in identifying and addressing restrictive practices from a human rights-based approach. Quality-improvement thematic inspections were not undertaken in these centres. Instead, inspectors continued to undertake risk-based regulatory inspections in these services.

For example, on one risk-based inspection inspectors found that a prescribed support for the use of an essential aid at night to lessen the risk of harm from an unintended injury meant that the resident could no longer use the call-bell to call staff for assistance. The provider's response to this was to place an audio monitor in the resident's room. However, the provider did not recognise that the use of such a monitor impacted on the resident's privacy nor did it see it as a restrictive practice. There was also no evidence that the use of the monitor had been discussed with the resident or that their consent had been sought.

In other centres, inspectors continued to find that historical 'custom and practice' resulted in unintended or collective restrictions on the rights and dignity of residents. For example, some residents were not able to access their own money independently whenever they wished. Other findings which negatively impacted on the quality of life of residents in some centres included:

- none of the residents being allowed to have a cup of tea in their rooms,
- door alarms were in constant use to monitor the movement of people around the centre,
- hourly night checks were routinely completed for residents where there was no clinical need to do so,
- and there was a continued reliance on centralised kitchens and set mealtimes.

3.3. Next steps in thematic monitoring of restrictive practices

Findings from these inspections are shared with the providers and published by HIQA regularly. In addition, in 2019 a series of information roadshows for providers was attended by over 500 managers and representatives from service providers and centres around the country. High-level anonymised findings from the programme of thematic inspections were shared and discussed from a human-rights perspective with everyone attending. Further information on the restrictive practice thematic inspection process can be found at www.hiqa.ie.

Chapter 4. Registration and inspection activity in 2019

4.1. Introduction to registration and inspection

The regulations are put in place by the State and set out the minimum standard of safety, care and support that a provider must achieve for residents. Providers and funders of services are responsible for complying with these minimum regulations, while the Chief Inspector monitors providers' compliance with the regulations. The national standards challenge providers to continually review and improve the quality of their services, and to go beyond compliance with the minimum requirements of the regulations.

The framework⁷ for regulating designated centres for people with disabilities (including children) is set out in law in the Health Act 2007 (as amended). This is underpinned by associated regulations and is supported by the national standards. In 2019, to support providers and staff of designated centres, HIQA published a *Regulation Handbook*, which covers all aspects of registration and regulation. It can be found on www.hiqa.ie.

Designated residential centres for children and adults with disabilities must be registered by the Chief Inspector, and registration is granted for three years. The lived experiences of people with disabilities (such as 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 how the sector is regulated by the Chief Inspector.

4.2. The number and type of designated centres

The numbers of designated centres for people with a disability continued to increase in 2019. At the end of 2019, there were 1,268 registered designated centres, which represents an increase of 85 registered centres during the year. These centres provided residential accommodation for 9,064 people with disabilities compared with 8,894 residential placements at the end of 2018, a growth of 2% in the sector.

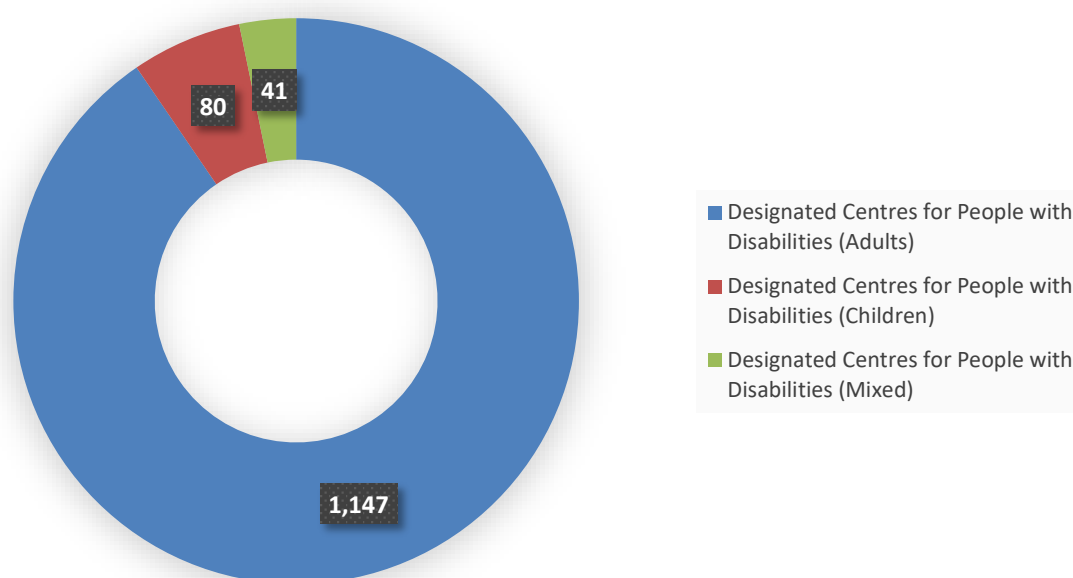
The breakdown in the type of designated centre is shown in Figure 20. By year's

⁷ 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).

end, out of 9,064 people with disabilities living in designated centres, 8,457 residential places were in centres for adults with disabilities, 347 were in children's centres and 260 were in mixed centres where both children and adults lived. Most of these mixed centres were respite services which provided breaks to adults and children separately.

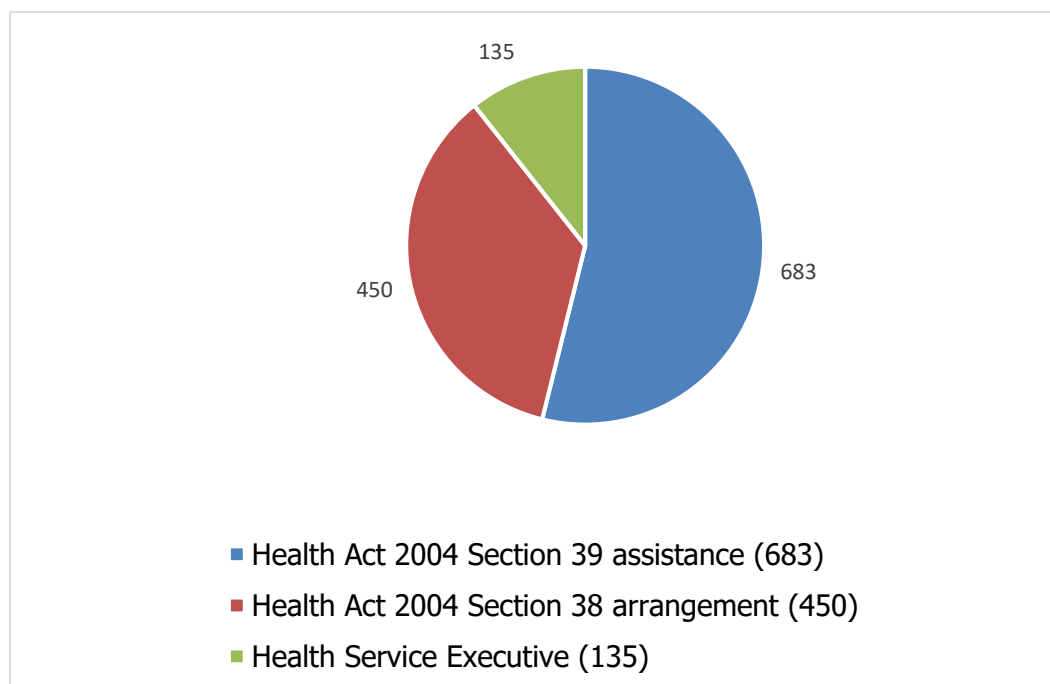
Figure 20. Number and type of designated centres for people with disabilities at the end of 2019



The increase in the number of designated centres can be partially attributed to the creation of a number of centres to support residents to move out of larger congregated settings into more appropriate community settings. In addition, some people with disabilities who were living at home with their families needed residential care because their supports at home were either no longer available or were unable to meet the residents' needs.

Designated centres for people with disabilities are provided by a number of different bodies. The funding arrangements for these centres changed little in 2019, with most centres either being directly provided by the State through the Health Service Executive (HSE) or provided by organisations funded by the HSE. Figure 21 provides the breakdown of designated centres for people with disabilities by the type of provider funding model at the end of the year.

Figure 21. Number of registered designated centres for people with disabilities by provider funding type at 31 December 2019



The HSE directly provided 1,116 residential places (12.3%) in a total of 135 centres. A total of 5,109 places (56.4%) were provided by organisations funded through HSE-funded section 38⁸ arrangements in a total of 450 centres, and 2,839 residential places (31.2%) were provided through HSE-funded section 39⁹ assistance in 683 centres.

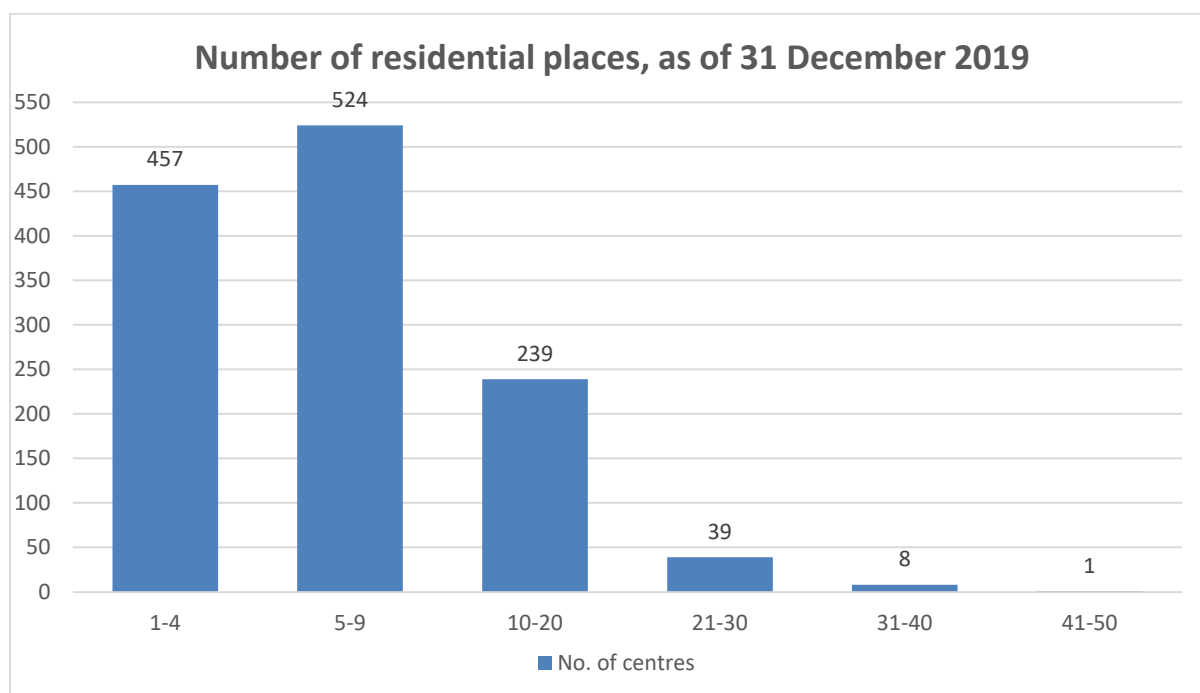
4.3. The size of disability centres

Residential centres for people with disabilities range in size from single occupancy centres up to large congregated institutional settings (see Figure 22 for details). In addition, some community-based houses are grouped into a single designated centre and some designated centres are accommodated on the same campus. The Chief Inspector maintains an online register of all disability centres, which is available at www.hiqa.ie.

⁸ Section 38 of the Health Act 2004 states that the HSE can have an arrangement with a person to provide a health or personal social service on behalf of the HSE.

⁹ Section 39 of the Health Act 2004 states that the HSE can provide assistance to any person or body providing a similar service to the HSE.

Figure 22. The number of residential places in designated centres



Note to table: the figures on the top of each bar represents the number of designated centres. So, for example, there are 457 centres with between one and four places in each centre.

After regulation of the sector began in 2013, an extension of the deadline for registration was granted by the State to allow providers additional time to achieve the basic requirements of the regulations. In 2018, the Chief Inspector completed the first full cycle of registration for designated centres for people with disabilities. For the first time, all designated centres for people with disabilities were registered. As a result, 2019 was the first year that there was complete and validated data about the range and number of residents living in these centres.

Of the 9,064 residential places registered by the end of 2019, nearly one in three residential places (32% or 2,914 places) continued to be located in congregated settings. Of these 2,914 places, 2,368 residential places were in campus-based settings. Usually, these large campuses are divided into a number of centres and while the number of residents in each centre may vary, all of them are based on the same site. Five hundred and forty-six places were in stand-alone congregated settings for 10 or more people.

4.4. Congregated settings

While there has been a concerted effort within the residential disability sector to reduce and ultimately close all large congregated settings (large institutions) in line with the HSE's national policy, many residents continue to be accommodated in congregated settings, as the above figures show. The national policy on congregated settings¹⁰ defines a congregated setting 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.

This overview report demonstrates that residents who live in congregated or campus-based settings often experience inequalities in terms of the quality and safety of their services, control over their own lives and their ability to independently exercise their rights and choices. Chapter 2 of this report highlights how the human rights and choices for people with disabilities are negatively impacted by the kind of designated centre that they live in.

4.5. Registration activity in 2019

The Chief Inspector maintains a register of designated centres for people with disabilities which have been inspected and are deemed to meet a level of regulatory compliance that allows them to be registered. There was an overall net increase of 85 registered centres during 2019 (taking into account the closure of other centres during the year).

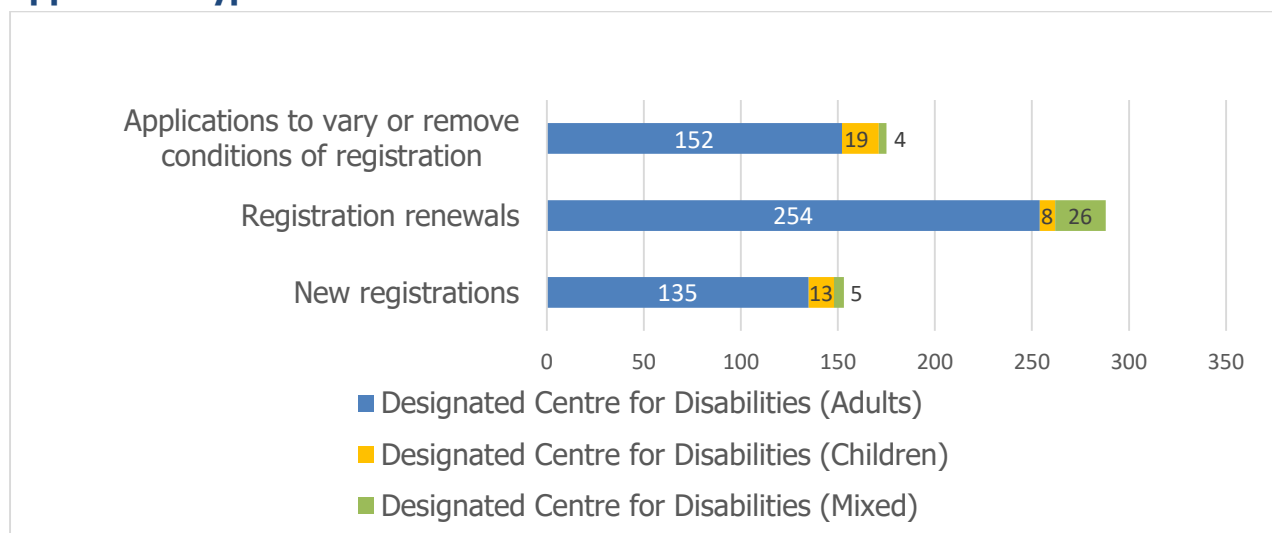
Each designated centre is granted registration for three years and must then apply in advance to renew their registration. Designated centres which increase in size by extending their overall floor footprint must also complete a new application to register. In 2019, there were 153 new applications to register, while 288 centres had their registration renewed.

Providers can apply to vary or remove conditions of registration; for example, to increase or decrease the number of residential places that the centre is registered for. In 2019, there were 175 applications to vary or remove conditions of registration in designated centres for people with disabilities.

¹⁰ Health Service Executive. *Time to move on from congregated settings - A strategy for community inclusion*. Dublin, Health Service Executive; 2011. Available online from: <https://www.hse.ie/eng/services/list/4/disability/congregatedsettings/time-to-move-on-from-congregated-settings-%E2%80%93-a-strategy-for-community-inclusion.pdf>.

Figure 23 shows the breakdown of the applications received across adult services, children's services and mixed services for people with disabilities, which indicates the level of registration-related activity undertaken during the year.

Figure 23. Number of notices of proposed decision issued in 2019 by application type



4.6. How compliance is judged

Inspection is a fundamental component of the assessment of compliance with regulations and national standards. HIQA takes a risk-based approach to regulation. Therefore, more frequent inspections are carried out in those centres which have higher levels of repeated non-compliance with the regulations and standards. Inspectors want to know whether people who are receiving residential care and support:

- are safe
- have their human rights respected
- are included in decisions about their care and support
- are provided with care and support that matches their individual health and social needs
- are living in suitable, fit-for-purpose environments and
- have a good quality of life.

4.7. Inspection activity in 2019

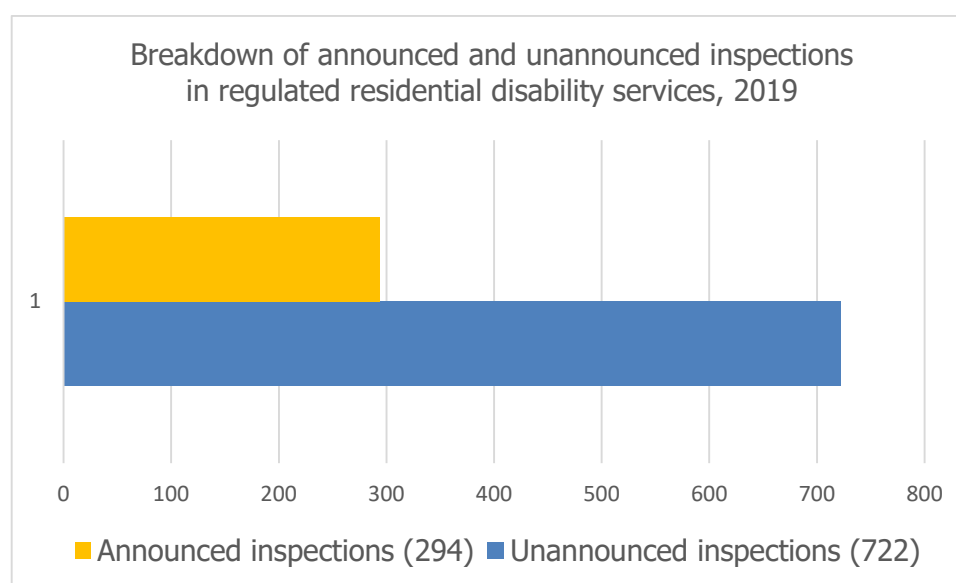
On-site inspections allows inspectors to observe the daily routine of residents, to hear from them about what it is like to live there or to observe interactions between staff and residents. It also helps inspectors to judge the provider's compliance with the regulations and how their level of compliance affects the lived experience of residents. For this reason, inspections can be announced or unannounced.

Announced inspections enable residents and relatives to meet the inspector by letting them know in advance when inspectors will be present in the centre. An inspection may also be announced if the inspector requires a particular member of staff to be available during the inspection. Unannounced inspections can happen at any time of the day or night and on any day of the week.

In 2019, inspectors carried out 1,016 inspections in 895 designated centres for people with disabilities (see Figure 24). Of these, 240 centres were inspected in order to inform a registration renewal decision. Inspectors carried out 776 inspections to check compliance with regulations and or whether providers were ensuring the safety, care and welfare of residents. As seen in Figure 24, 722 inspections (71%) were unannounced while 294 (29%) were announced.

In all, 949 centres were inspected at least once during 2019, including 54 which had a restrictive practice thematic inspection. See Chapter 3 for more details on this thematic inspection programme. While not all centres were inspected during 2019, all centres are inspected at least once during their registration cycle.

Figure 24. Breakdown of announced and unannounced inspections in 2019



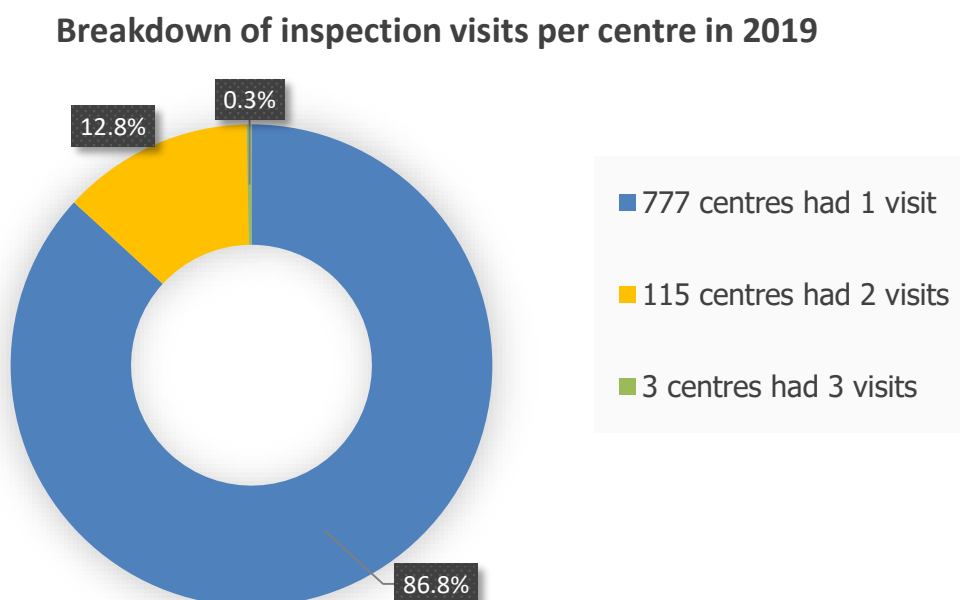
For some residents, the unannounced arrival of visitors to their home can be a difficult experience. In these circumstances, inspectors may decide to give advance notice of the inspection or modify the timings of inspections in line with information previously given to inspectors by either the residents or providers.

4.8. Centres requiring repeat visits in 2019

The Chief Inspector ensures that providers who are failing to comply with the regulations are 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 these improvements must be made. More frequent inspections may take place in these centres in order to gather evidence and to monitor the provider's progress and the impact of the provider's actions on the safety and quality of life of residents.

In a welcome development, fewer centres required a repeat inspection in 2019 when compared with the previous year. Of the 895 centres inspected in 2019, 777 of these received one inspection. This was because they had a good level of compliance and, where there were non-compliances, the provider responded appropriately. A total of 115 centres required two inspections, while three centres required three inspections (see Figure 25). This compares favourably with 2018 when seven centres required three or more inspections and reflects improving levels of compliance in the sector.

Figure 25. Level of inspection activity for centres inspected in 2019



4.9. Publication of inspection reports

The publication of inspection reports aims to increase transparency around how services are being run by providers and how services are regulated.

By the end of 2019, 863 inspection reports had been published. Some reports of inspections carried out in late 2019 were published in early 2020. In addition, some reports were not published in order to protect the privacy of residents where the contents of a report could result in residents being identifiable. In such cases, the provider must make a copy of the report available to residents.

Further information on the publication process is contained in the Regulation Handbook, available on www.hiqa.ie. In addition to individual inspection reports, HIQA's annual report also contains data on our inspections, while an overview report is also made available annually.

4.10. Feedback on inspection reports and submissions

Before an inspection report is published, providers are given the opportunity to comment on and provide feedback on the factual accuracy of reports and on inspectors' regulatory judgments. This ensures that the provider has a fair and reasonable opportunity to consider the evidence in the report. After providing feedback, providers can later make a submission on judgments to the Chief Inspector when it disagrees with a judgment being made.

Where the Chief Inspector agrees with the original judgment, no change is made to it in the inspection report. However, the text of the report may be amended to provide readers with greater clarity. Where a judgment is not upheld, the Chief Inspector may either decrease or increase the judgment of the level of compliance in the report based on the evidence presented. This process ensures that each report is a fair and proportionate representation of a provider's service.

In 2019, the Chief Inspector received submissions from providers in response to three inspection reports for centres for people with disabilities. A total of five judgments across these three reports were appealed. In each of these, based on the evidence presented, the Chief Inspector upheld the original judgments of the inspector. However, in two out of the five upheld judgments, the Chief Inspector recommended changes be made to the narrative in the reports in order to provide greater clarity.

4.11. Notifications of incidents, events and changes

Inspections provide first-hand information about the quality and safety of services. In addition, inspectors continually monitor all centres, based on information received through a number of channels, including mandatory notifications from providers of incidents, events or changes that happen in the centre. Inspectors assess this information to identify any changes or trends in the centre which might alert inspectors to the need to take further regulatory actions.

In 2019, inspectors processed 21,615 such notifications from designated centres for people with disabilities (see Figure 26). This is an increase of 3,378 compared to 2018.

Figure 26. Number of notifications received in 2019



The vast majority (10,304) of these were monitoring notifications which are required by the care and welfare regulations. These relate to specific instances that may occur in the centre in relation to the safety and wellbeing of residents and the operation of the centre. Most of these must be submitted within three working days of the event (see Figure 27) with others required to be submitted on a quarterly basis.

The Chief Inspector encourages providers to submit the required notifications via the HIQA Provider Portal. A large number of notifications does not necessarily imply there is a risk of non-compliance with the regulations or poor outcomes for residents. Further information on the notifications process can be found in the Regulation Handbook.

Figure 27. List of significant events which require notification to the Chief Inspector within three working days

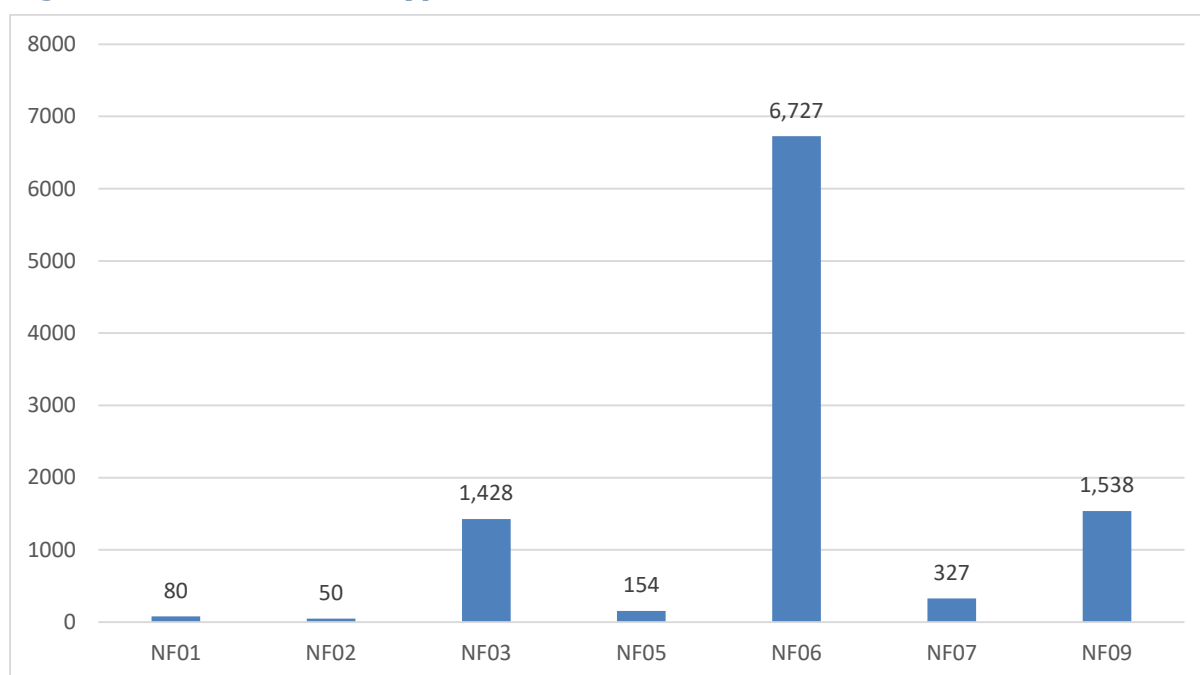
Form number	Title of monitoring notification required
NF01	The unexpected death of any resident, including the death of any resident following transfer to hospital from the designated centre
NF02	An outbreak of any notifiable disease as identified and published by the Health Protection Surveillance Centre
NF03	Any serious injury to a resident that requires immediate medical or hospital treatment
NF05	Any unexplained absence of a resident from the designated centre
NF06	Any allegation, suspected or confirmed, of abuse of any resident
NF07	Any allegation of misconduct by the registered provider or by staff
NF08	Any occasion where the registered provider becomes aware that a member of staff is the subject of review by a professional body
NF09	Any fire, loss of power, heating or water, or unplanned evacuation of the designated centre

The highest number of notifications received related to NF06 (safeguarding concerns) — allegations, suspected or confirmed, of abuse of any resident (see Figure 28). Many of these notifications relate to altercations between residents in centres and do not necessarily mean that there is an immediate risk of abuse to residents in the centre.

Each notification is assessed by an inspector who considers how the provider has responded to the situation, while the inspector also checks previous trends and overall information about the centre. Where ongoing risk is identified or where there has been a failure to respond effectively, further regulatory action will be taken.

Each of these notifications was risk assessed within three days of receipt, and where required, additional assurances were sought to confirm that the provider had taken the necessary action to safeguard each resident. Notifications are routinely followed up during inspection activity and are used to inform regulatory decisions up to and including enforcement.

Figure 28. Number and type of notification received in 2019

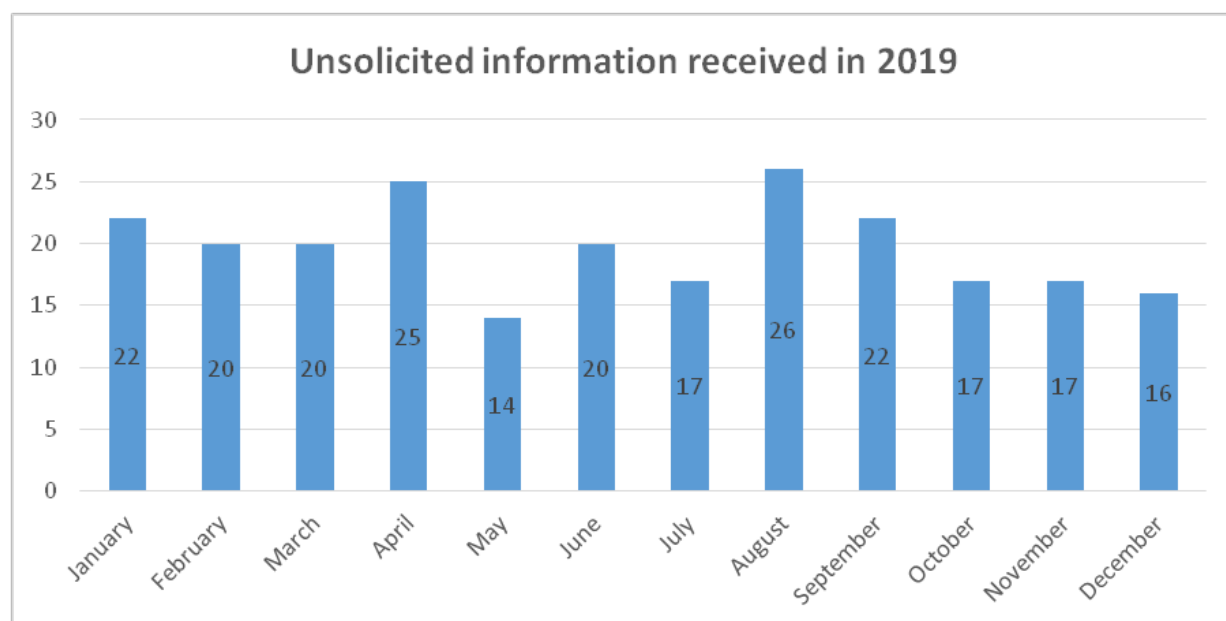


Where necessary, HIQA will notify other relevant agencies about concerns which have not been notified to them already by a provider. These agencies include An Garda Síochána, the Child and Family Agency (Tusla) or the HSE National Safeguarding Office. In 2019, inspectors in the disability section made three referrals to the HSE National Safeguarding Office, two referrals to Tusla, one referral to An Garda Síochána and one referral to An Bord Pleanála.

4.12. Information of concern

HIQA also receives information of concern about services from residents, their families and from members of the public and other sources. This information is used to support regulation. During 2019, 236 pieces of unsolicited information were received relating to designated centres for people with disabilities (see Figure 29).

Figure 29. Monthly breakdown for receipt of unsolicited information in relation to designated centres for people with disabilities



The types of concern received can vary and include concerns relating to:

- admissions and contracts for residential placements
- responses to complaints made within the centre
- residents' access to their local community
- the general welfare and development needs of residents
- governance and management of a centre
- health and safety matters
- risk management
- healthcare
- medicines management
- residents' rights
- premises
- safeguarding and safety
- social care needs and workforce.

All items of unsolicited information are individually risk assessed and appropriate action is taken by the inspector in relation to each concern. This may mean that the provider is required to undertake a review of its service or that an unannounced inspection is completed. In addition, with the consent of the person raising the concern, this information may be referred to another agency for further follow up if that is appropriate.

Conclusion

The regulation of centres for people with disabilities ensures that there is regular, independent monitoring of the safety and quality of care and support being provided to residents. The registration process means that providers have to demonstrate that they are meeting the minimum basic requirements set out by the State in the regulations, and that they are also striving to achieve ongoing quality improvement in their services through the national standards.

Inspectors monitor providers through inspection and through review of information received from providers and from the public. Where providers are found to be failing to provide residents with the quality of service that they are entitled to, the Chief Inspector can undertake a range of enforcement actions to ensure that action is taken to prioritise the rights and the welfare of residents. This is discussed in Chapter 5 of this report.

Chapter 5. Escalation and enforcement

5.1. Introduction to actions to protect residents

Where inspectors find that poor compliance results in a very poor quality of life for residents or leads to a high risk of harm, the Chief Inspector can take a number of steps — ‘escalation and enforcement’ — to bring providers into regulatory compliance and protect residents and improve their lives.

In such cases, the Chief Inspector can increase regulatory activity up to and including the decision to take enforcement action (which can include closing the centre). Whenever such activity happens, the Chief Inspector will always try to minimise disruption and anxiety for people living in designated centres.

During 2019, most providers of designated centres operated good quality services. These providers focused on building high levels of compliance which improved the quality and safety of care. However, during the year, the Chief Inspector took action against a number of providers when the rights of residents were not being promoted and protected.

In 2019, 54 centres (4.25% of the 1,268 registered designated centres) were the subject of increased regulatory actions and additional targeted monitoring and scrutiny of the provider’s improvement plans.

Actions included issuing warning letters and holding warning meetings with providers. Such actions are taken to communicate to providers where improvements are required and when they are required by. In the vast majority of cases, these types of escalated actions were sufficient and resulted in providers taking the necessary measures to bring the centres into compliance.

However, others needed further action, including a requirement for the provider at organisational level to develop and implement a management improvement plan across its services.

5.2. Provider warning letters and meetings

Warning letters set out the areas of significant concern which may, if unresolved, result in the Chief Inspector deciding to cancel the registration of a centre or attach an operating condition to the registration of a centre (such as placing a limit on the number of people who can live in a centre). The Chief Inspector may also warn providers that they may be prosecuted.

In 2019, the Chief Inspector issued 90 warning letters to 20 providers. In most cases, the warning letter improved the quality of the service and led to providers bringing the centre into compliance with the Health Act 2007 (as amended) and the regulations. However, in a number of cases, further escalated regulatory decisions were required, which are set out below.

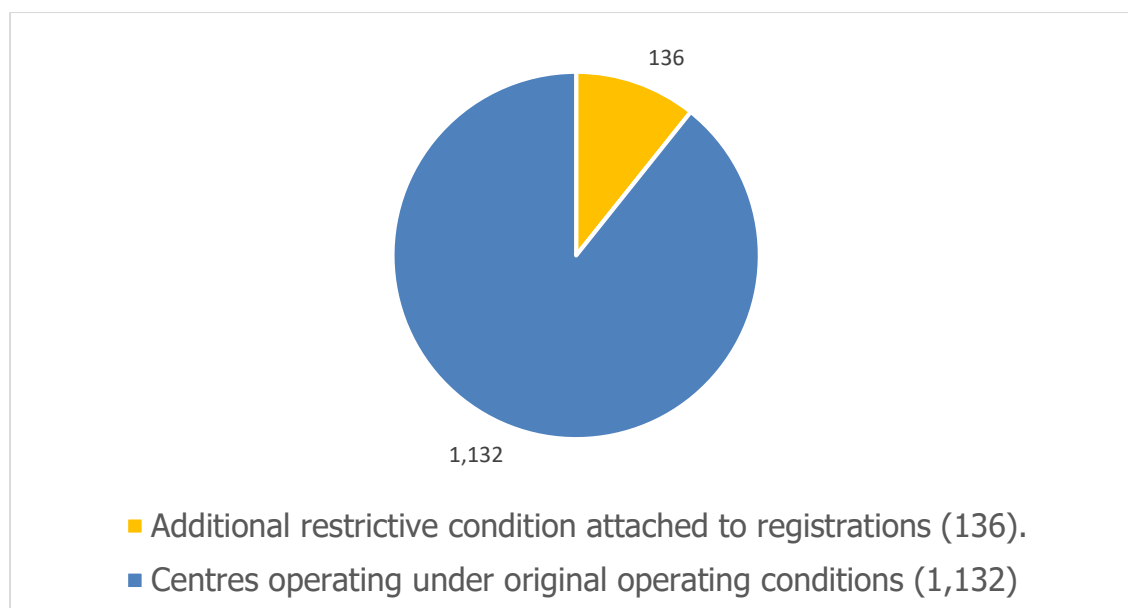
5.3. Attaching conditions of registration

The Chief Inspector attaches specific conditions to all registrations which are granted, and which relate to providers complying with their statements of purpose (the scope of the service), the age range of residents and the number of residents that can live in a centre. These types of conditions are called 'permissive' conditions.

However, on occasion, the Chief Inspector may decide to attach further conditions to a centre's registration. Those might include requiring the provider to improve the management of the centre, reduce or limit the number of residents living there or enhance the premises. These types of conditions are referred to as 'restrictive' conditions, and they make it clear to providers that they must meet these conditions in order to continue to be registered.

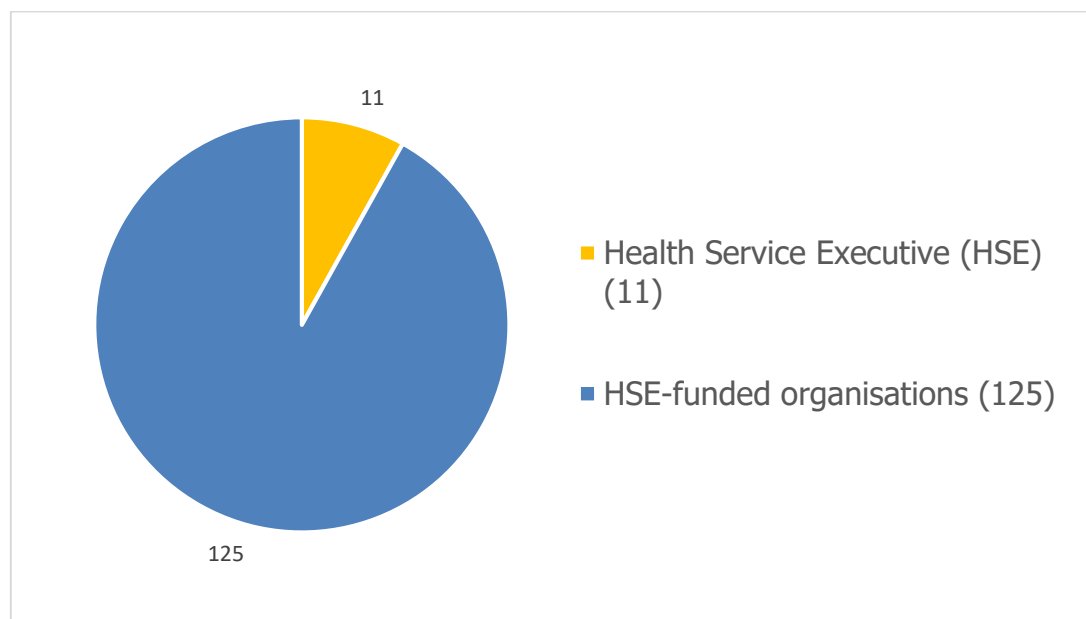
Overall, in 2019, the vast majority (89%) of designated residential centres for people with disabilities operated their services without the requirement for additional, restrictive conditions (Chart 1). This indicates that they either have good levels of compliance with regulatory requirements or have demonstrated an ability to rectify any areas of non-compliance that are impacting on the quality of life and consistency of service being provided to residents.

Chart 1. Breakdown of centres requiring additional operating conditions to be applied at the end of 2019



However, at the end of 2019, 136 registered centres had a restrictive condition attached to their registrations. In five of these centres, more than one restrictive condition was attached to the centre's registration. This led to a total of 142 restrictive conditions in the 136 centres. The HSE was the provider of 11 of these centres; the remaining 125 centres were HSE-funded organisations (Chart 2). In total, 55 of these centres were congregated or campus-based settings.

Chart 2. Breakdown of type of provider which had restrictive operating conditions attached to the registration of their centres at the end of 2019



Each restrictive condition required the provider to improve aspects of the service within a time frame set out by the Chief Inspector. Providers who have restrictive conditions in place are required to submit regular updates on progress (or not) being made towards achieving the required actions. Where providers satisfactorily show that they have taken the necessary steps to resolve the issues which gave rise to the restrictive condition, they may apply to the Chief Inspector to have it removed from their registration.

5.4. Notices of proposed decision to cancel, refuse or attach

In line with the powers in the Health Act 2007 (as amended), the Chief Inspector issued notices of proposed decision to cancel the registration of four centres during 2019. This was due to repeated findings of regulatory non-compliance and concern about the care and welfare of residents. The Chief Inspector also issued notices of proposed decision to refuse the application to renew the registration of four other centres because of the failure of the provider to ensure residents were in receipt of a quality of service that they were entitled to.

The decision to issue notices of proposed decision to cancel or refuse applications to register is not taken lightly, given that such actions can cause much distress and anxiety for residents and for their families. Providers are usually given ample opportunity to address the failings in the service before the Chief Inspector considers issuing such notices. In most cases, such notices are only issued after the provider has failed to improve the quality of its service following a number of other actions taken by the Chief Inspector.

Three of the four providers which received a notice of proposed decision to cancel the registration of their centres in 2019 successfully addressed the issues of concern outlined in these notices. As a result, the Chief Inspector withdrew the notices of proposed decision to cancel the registration of those three centres. At the time of writing, a decision on whether to proceed to cancel the registration of the remaining fourth centre was under consideration by the Chief Inspector.

Of the four centres issued with a notice of proposed decision to refuse their renewal application, the provider of one centre took the necessary required actions, and this centre was later registered. However, three providers failed to demonstrate sufficient improvement. Continuing concerns about the care and welfare of residents resulted in the Chief Inspector issuing 'notices of decision' (the next step in the process) to refuse the renewal of the registration of these three centres in 2019.

Where the existing registration of a designated centre is cancelled, under section 64 of the Health Act 2007 (as amended), the HSE is required to take over responsibility for operating the centre. As of the beginning of 2019, eight designated centres which had previously had their registration cancelled by the Chief Inspector — because of poor quality of care and support for residents — were being operated by the HSE under a section 64 arrangement.

During 2019, two of these centres closed, and the residents living in these two centres moved into new designated centres. Routine follow-up inspections of these new designated centres following their successful registration for the first time found that residents living in these centres had a much better quality of life and a much improved living environment.

Chapter 6. Concluding statement

The role of the regulator is to monitor regulated services against the basic requirements set out by the State in the regulations and to consider whether providers are implementing ongoing quality improvements using the *National Standards for Residential Services for Children and Adults with Disabilities*. Responsibility for providing a good service to people with disabilities living in regulated residential centres rests with both providers and funders.

The Chief Inspector's regulatory findings in 2019, once again, show the critical link between good governance and safety and a good quality of life of residents. Providers who had good governance and oversight arrangements in place were delivering services that had higher levels of compliance with the regulations and provided better outcomes for residents. Providers with poor levels of compliance had inadequate oversight and oversight systems in place, which in turn led to poorer outcomes for residents.

During 2019, the Chief Inspector worked with residents, families, advocates and providers to continue to improve services and the human rights of people with disabilities living in designated centres in Ireland. Notwithstanding this engagement and the new challenges arising in 2020 from COVID-19, this report demonstrates the difference in the safety and quality of life between residents who live in the community and those who continue to live in large institutions or in campus settings.

Residents who moved to smaller community homes consistently told inspectors in 2019 that they were happier and had a better quality of life compared to when they lived in campus or congregated settings. For the one in three people living in congregated or campus-based settings, more work is needed to ensure that they are supported to move into smaller homes in the community. This is in order to promote the personal freedoms and control over their own lives that they are entitled to.

In the early days of regulation, inspectors initially found that most centres were providing residents with a good quality of life. However, they also found many centres where people with disabilities were living in shocking conditions in old and poorly maintained environments. These were often, but not always, these same large institutions with historical issues where providers were failing to protect residents from regularly experiencing harm and injury from their peers.

Regulation has made a major contribution to identifying unacceptable living conditions for people with disabilities. The regulatory framework has been a catalyst for changes to improve the safety and the quality of life of residents. However, this work is not yet complete. As can be seen from the outcome of inspections during

2019, people living in congregated settings are at greater risk of having a poor quality of life.

In recent times, providers have developed services for residents that mean their new homes fall outside of the current definition of a regulated designated centre under the Health Act 2007 (as amended). Usually, these developments are innovative and respond well to the assessed needs of the person with disabilities. However, while welcome, there is a risk that people with disabilities living in these services will no longer have independent oversight of such services.

Therefore, this is an opportune time to review the definition of a designated centre under the Act in order to offer regulatory protection for all models of residential care for people with a disabilities. In the meantime, the Chief Inspector will continue to use the existing regulatory framework to promote service improvements and the rights and quality of life of people with disabilities living in designated centres in Ireland — particularly those in campus and congregated settings.

At the time of preparing this report, the COVID-19 pandemic continues to affect how each of us live our day-to-day lives. The pandemic undoubtedly poses huge challenges to the 9,000-plus people with disabilities living in designated centres, and their families, friends, advocates and providers. HIQA is committed to continuing to engage with residents during inspections under COVID-19 and to develop ways to safely meet residents outside of the inspection process.

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