Health Information and Quality Authority

An tÚdarás Um Fhaisnéis agus Cáilíocht Sláinte

10 YEARS OF REGULATING

DESIGNATED CENTRES FOR PEOPLE WITH DISABILITIES

2013 - 2023

About the Health Information and Quality Authority

The Health Information and Quality Authority (HIQA) is an independent statutory body 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.

Reporting to the Minister for Health and engaging with the Minister for Children, Equality, Disability, Integration and Youth, 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 of Social Services 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 permanent international protection accommodation service centres, health services and children's social services against the national standards. Where necessary, HIQA investigates serious concerns about the health and welfare of people who use health services and children's social 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 and social care services, with the Department of Health and the HSE.

Visit www.hiqa.ie for more information.

About the Chief Inspector of Social Services

The Chief Inspector of Social Services within the Health Information and Quality Authority (HIQA) (referred to in this report as the Chief Inspector) is responsible for registering and inspecting designated centres in Ireland.

The functions and powers of the Chief Inspector are set out in Parts 7, 8 and 9 of the Health Act 2007 (as amended) (from now on referred to in this report as the Act).

The Chief Inspector currently regulates designated centres for:

- older people
- people with disabilities
- special care units for children.

The role of the Chief Inspector includes inspecting and registering designated centres for people with disabilities through assessing compliance with the regulations and nationally mandated standards. This is achieved through desktop inspection of information received from the provider and unsolicited information from other sources about the designated centre, on-site inspection in designated centres and ongoing assessment of compliance by providers with the regulations and national standards. The regulations and standards in effect for designated centres for people with disabilities are 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
- Health Act 2007 (Registration of Designated Centres for Persons (Children and Adults) with Disabilities) (Amendment) Regulations 2015
- *National Standards for Residential Services for Children and Adults with Disabilities* (2013)
- *National Standards for infection prevention and control in community services* (2018)
- *National Standards for Adult Safeguarding* (2019).

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Foreword from the Chief Inspector of Social Services

Carol Grogan, Chief Inspector of Social Services

I am pleased to present this report which describes our experience, as a regulator, of inspecting residential disability services over the past decade and the positive impact on the lives of residents. Before 2013 — when regulation was first introduced to the sector — there was no independent monitoring of the quality and safety of services and the experiences of residents. At that time, as a nation, we were still emerging from the global financial crisis, and austerity measures were limiting the resources available for health and social care services. This represented a huge challenge for providers of disability services as it limited funding at a time when they were being asked to improve quality to meet the regulations.

When we started our inspections, we found many good or excellent services. However, we also found a significant cohort of centres where there were very poor and concerning care practices, particularly in 'congregated settings' where large numbers of residents were living together. Some services had unfit premises, insufficient staffing levels and institutional practices where residents did not receive person-centred care. Residents should have been involved and consulted on their care, they should have felt safe in their homes and their rights should have been upheld. Unfortunately, this was not always the case in the early years of regulation. One of our challenges at this time was to demonstrate to the poorly-performing providers that residents should be at the centre of everything they did.

Inevitably, some providers were not capable of this transformation, and we used our powers of regulatory action and enforcement where necessary to ensure those centres were taken over by alternative providers. As the decade progressed, we observed a gradual improvement across the vast majority of residential services. Last year, we found that a human rights-based approach to care was clearly being embedded in services. Many of the providers that were not performing well in the early years managed to change the culture in their centres and improve the quality of life for residents. Providers that had been already performing well looked for ways they could build on their success and achieve higher quality. Many residents moved from large institutional-style residential settings into community-based settings which could better meet their needs.

Over the past 10 years, we have seen countless examples of lives transformed for people who have moved from institutional settings, such as large multi-storey buildings or large campuses to more person-centred services in the community, such as living in a family home in a housing estate in a town or city, or a house in a local rural setting.

Our approach to regulation has also evolved over the past 10 years. We have sought to improve how we engage with residents, both during and outside of inspections, and we have given greater prominence to their voice in our inspections and reports. We have met with many residents over the years and are immensely thankful to each of them for welcoming us into their homes and for sharing their experiences with us. We have also met with the providers and staff, and observed kind compassionate care and support. We have witnessed a move to understanding and embedding rights-based care and support where the resident is central to all decisions about their care and support.

We have also carried out what we refer to as 'thematic programmes' which focus on improving the quality of specific areas of care and support, such as promoting greater liberty and independence of residents through reducing what are termed 'restrictive practices'. These inspection programmes are having a significant positive impact on the lives of residents.

Notwithstanding the progress, there are significant current and future challenges facing the sector. The pace of progress with decongregation (moving residents from large institutional settings to family homes in the community) is slow and requires extra impetus from all stakeholders, particularly in light of the benefits observed for those that move into the community. The sector is also experiencing challenges in recruiting and retaining staff, as well as in sourcing suitable properties for residents to live in. A national strategy is required so that as a country we can have a clear vision for how social care is to be provided, funded and staffed into the future to meet the needs of those who require care and support. Our goal, collectively, should be that all people with disabilities can live active and fulfilling lives where their human rights are protected and promoted. We will continue to work with residents, their families, friends and advocates, providers, staff and other stakeholders towards achieving that goal.

Carol Grogan

Chief Inspector of Social Services, Health Information and Quality Authority

Executive summary

Regulation provides assurances to people with disabilities, their loved ones, society and the State that residents in designated residential centres are being provided with a quality of care and support that they are entitled to.

This report describes the experience of the Chief Inspector of Social Services within HIQA of regulating disability services over the past 10 years.

This report sets out the impact of regulation over that time frame, detailing our key findings and learnings in the key areas of governance and management, a human rights-based approach to care, restrictive practices, safeguarding and protection, and general welfare and development, as well as reflecting on current and future challenges for the sector.

Commencement of regulation

The introduction of regulation provided a framework to identify and respond when things go wrong, and to support providers to improve the quality of support and care for people with disabilities living in designated centres. Regulation, including the receipt and monitoring of information and conducting inspections, ensures that when things do go wrong, they are identified quickly. It provides a means of ensuring that those poor practices are not perpetuated within centres, as had been the case in the past.

When we commenced regulation of designated centres for people with disabilities in 2013, we found that the majority of centres were good and were meeting residents' support needs, and there were many excellent services which provided high-quality care and support. However, a significant cohort of centres inspected were very poor, posing a risk to the safety and quality of life of people living there. This included the use of institutionalised practices, where poor practices were embedded in services and residents had been experiencing them for years, and decades in some cases. Providers and staff working in these settings had failed to recognise the negative impact these practices had on people living in those centres.

Much of our role in the early years of regulation was to challenge these poor providers and highlight poor practices. For example, unsuitable living conditions on campus-based or congregated settings, where some residents had no choice over their day-to-day life or living arrangements, such as having to spend their days in large group settings where there were constantly high levels of noise and where residents often hurt or threatened other residents. Other examples included the prevalent use of restrictive practices, such as physical or chemical restraint to restrict residents' movements, or ineffective risk management where there were weak systems in place to safeguard residents from the risk of abuse.

Furthermore, we have consistently found that where there is poor governance, there is a negative impact on residents as a result.

Impact of regulation

Prior to regulation in 2013, there had been little or no accountability in centres where residents had experienced a very poor quality of life. Over the past decade, regulation has had a positive impact on the lives of people living in residential centres and has influenced change in the sector. We have used our powers, including taking escalation action up to and including cancelling a centre's registration where necessary, to protect residents and promote their rights, care and welfare.

From 2013 to 2023, HIQA's Chief Inspector has:

- carried out over 9,400 inspections of services
- registered over 1,500 centres for over 9,000 people
- cancelled the registration of 15 designated centres where there were significant concerns
- received 2,623 concerns about services, an average of 238 per year.

At the end of 2023, there were 1,574 centres offering 9,147 places for people with disabilities.

Through our inspection reports and the use of compliance plans, providers are held to account for non-compliance, and we use our powers to follow up with them to ensure they put measures in place to address areas of risk or concern. The publication of these reports allows for transparency for people using services, their families and the public.

We have also used our powers and inspection reports to encourage registered providers to embed a culture of strong governance and management, and have advocated for and regulated to promote appropriate safeguarding in their services. In addition to our regulatory remit, we have also called for the introduction of legislation on adult safeguarding in Ireland. While transformation of governance and management can be difficult, it is achievable and has been observed by inspectors, as detailed in examples throughout this report. A provider's compliance is never static. Over the past 10 years, HIQA has seen good providers fall into non-compliance due to changes to management, staff and culture, as well as seeing previously poor providers make significant improvements.

Over the years, we have also evolved in our approach to regulation, moving from highlighting poor conditions to driving quality improvements across the sector,

specifically through the introduction of thematic inspections in key areas such as restrictive practices, to ensure that residents are supported to live fulfilling lives.

Decongregation

One key area where regulation has played a crucial role was in supporting the decongregation of institutional, campus-based settings. In many of these centres, particularly in the early days of regulation, the publication of inspection reports was the first time that there was full transparency on the poor living conditions for residents. Many of the poor practices observed by inspectors in those years was in these services. In line with the Health Service Executive (HSE)'s *Time to Move on From Congregated Settings* policy, decongregation has led to an increase in the number of centres that we regulate, as people moved out into community-based homes.

Regulation continues to ensure and provide for an improved quality of life for those residents who still live in congregated settings, and residents constantly tell us about the impact better living arrangements have had on their lives. However, the pace of decongregation has stalled, and new impetus is required to invigorate the programme to move people from large congregated settings.

Human rights

The government's ratification of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in 2018 underpinned the State's commitment to ensuring that people with disabilities are empowered to live independent and fulfilling lives.

This renewed focus on human rights has led to residents' voices being increasingly placed at the centre of both our own work and in the centres they live in, which is a positive development. We gather and include residents' feedback routinely on inspection, but also through our residents' forums that allow us to meet with residents outside of the inspection process. Residents hold the most important opinions on the quality of services and on our work, and we will continue to seek their views and include their voices in our reports and publications.

Over recent years, HIQA has promoted a human rights-based approach to care in services. Inspectors have reviewed and reported on the impact that training on a human rights-based approach has had on residents' lives in inspection reports. We have seen many examples of how residents' lives have been improved when staff have focused on upholding the fundamental human rights of residents.

Current and future challenges

While much progress has been made in improving quality in services and outcomes for residents over the past decade, there are significant challenges facing the sector now and into the future. With the transfer of the disability function from the Department of Health to the Department of Children, Equality, Disability, Integration and Youth, there is a new focus on the direction of travel for supports and services, as demonstrated by the launch of the three-year Disability Action Plan by the Government in 2024. However, there continues to be gaps in the legislation, such as the need to make provision for situations where providers need to accommodate people with disabilities in an emergency.

There is also a need for regulatory reform, to update the regulations to reflect current circumstances, such as the ratification of the United Nations Convention on the Rights of Persons with Disabilities, to strengthen the human rights-based approach within the regulations. New legislation, such as the Assisted Decision-Making (Capacity) Act 2015, provides a robust legal framework for people with disabilities that need support with making decisions. It is essential that residents can avail of such services so that they may protect and promote their own human rights.

Through our engagement with providers over the past number of years, we have heard about their difficulties with respect to several aspects of service delivery. For example, recruitment and retention of staff is an ever-present challenge and can be a barrier to the adequate resourcing of services. The difficulty of sourcing accommodation for new centres — part of the wider housing crisis — also represents a significant barrier for providers.

Conclusion

When we commenced regulation in 2013, there were many services providing good quality care. Others required significant improvements and we took action in the interests of residents where appropriate. We have observed improvements over the past decade and many providers have made great strides in promoting a person-centred approach to care. This report highlights some of these improvements in important areas such as the human rights-based approach to care, restrictive practice, safeguarding, general welfare and development and listening to and reporting on the voice of the resident.

There have been important milestones in the past decade which serve to strengthen the rights of residents. These include the *National Standards for Adult Safeguarding,* the Assisted Decision-Making (Capacity) Act 2015, publication of *Guidance on a Human Rights-based Approach in Health and Social Care Services*, and the ratification by Ireland of the United Nations Convention on the Rights of Persons

with Disabilities. As the regulator, we will continue to monitor the quality and safety of services and use our powers as appropriate to ensure that residents can live their best lives.

Chapter 1: Introduction — setting the scene

1.1 The impact of regulation on the lives of residents

In the first few years of regulating residential disability services, we focused much of our energies on those services that we had significant concerns about. We found that the majority of providers delivered good quality support to people with disabilities in designated centres. However, a significant number of centres provided very poor services and support, which had a significant impact on the safety and wellbeing of people living in their centres. Some poorly performing services closed, either voluntarily or as a result of enforcement action by the Chief Inspector. Notwithstanding this, we also saw a lot of poorly performing services managing to change the culture in their centres to one which respected and promoted the human rights of residents while attaining improved regulatory compliance levels.

As a regulator, we had only a high-level perspective on the quality and safety of services around the country at the time regulation started. Therefore, the early to medium period of regulation between 2013 and 2017 was a process of getting to know all of the various registered providers, assessing their performance and governance practices, and identifying the designated centres that were of the greatest concern with regard to quality and safety. In these first five years, each centre was required to go through the process of their first registration with the Chief Inspector.

The poor care practices and the precarious nature of some services found on some early inspections shocked our inspectors. These centres had often been funded to operate for many years without being effectively challenged in relation to their failure to ensure a safe and homely place for people with disabilities to live. These poor findings related mostly to institutional practices (such as regimented routines), ineffective risk management (including arrangements to prevent abuse and to promote fire safety), a lack of person-centred care, indiscriminate use of 'restrictive practices' and unsuitable premises. This report will look at how regulation has been an effective mechanism for improving residents' lives.

1.2 Examples of poor practice in the early period of regulation

Below are some examples from inspection reports that typify the poor standards of care that impacted on residents' quality of life in the early years of regulation. In one centre, inspectors found worrying restrictive practices in place during an inspection carried out in 2014:

'Time out' room for challenging behaviour

There was a room for use by residents, the walls of which were covered with thick, soft material, as were the floors. There was a significant amount of dust/stains on a number of the surfaces in the room and there was a strong, unpleasant odour. This room was initially described to inspectors as a 'soft play area'; however, other staff members described it as a 'time out' room that was used for some residents during incidents of challenging behaviour. There was no policy governing the use of the room to identify when it could be used, for what type of behaviour, the length of time that residents should spend there and the level of supervision required when residents were in the room.

In another centre, inspectors found one resident who spent their days strapped to a chair due to staffing shortages, and who required much support to recover their physical independence when the provider was required by inspectors to cease this unacceptable and institutionalised practice. In this centre, residents' rights to a safe and appropriate service that also upheld their basic human rights was not evident. Restrictive practices were in use throughout the centre, many of which had not been notified to the Chief Inspector as required. Staff knowledge about identifying and recognising restrictive practices was limited. The inspectors observed the inappropriate use of some of these restrictive practices, including that of a 'sleep suit' in use for a resident at night-time. The inspection report from 2017 noted the following:

Resident strapped to a chair

In one unit, inspectors observed a resident restrained in a reclined chair with a lap belt in place. Staff present stated that the resident could mobilise independently. The use of this restrictive procedure had been prescribed; however, inspectors found that it was not being used as outlined in the associated protocol. Staff present at the time confirmed that this restrictive procedure was used in response to reduced staffing levels. Inspectors reviewed associated documentation and found that this restrictive procedure had been used for 90 hours for this resident over a 19-day period prior to inspection.

In another service, the last admission to the centre had been 15 years before, and the inspector had concerns about weak governance and sustainability of the service, as outlined in the inspection report that followed:

Weak governance and no plan B

The person in charge informed the inspector that the centre… did not plan to recruit any staff in the traditional sense, describing the service as a 'way of life' with the five staff being involved in the service since its founding. The person in charge also emphasised the reliance upon this group of five, highlighting the fact that the service could not operate if one of these people had to cease this work for any planned or unplanned reason. For this reason, the longer-term planning needs and support requirements of the residents had not been considered and there was no form of succession planning in place. The person in charge/provider… acknowledged this was required for the residents living in the centre. It was not clear what would happen to the residents if the reliance upon the sense of commitment from the workforce could not be sustained, which directly impacts upon the sustainability of the service.

Up to the introduction of regulation in 2013, there had been little or no accountability in centres where residents had a very poor quality of life. Similarly, there had been no or limited opportunities for providers, managers and staff to reflect on practice and the negative impact it was having on residents. For example, listening to and responding to complaints is an essential and effective way for providers to ensure that their services are person-centred and meet the needs of people living there. Very often, there was a dismissive attitude to complaints or there was an overly informal approach to managing complaints, as seen in this inspection report from 2014:

Ineffective complaints process for residents and relatives

There was a local complaints policy; however, it did not outline, in sufficient detail, the process for managing complaints. It did not identify the complaints officer and even though it identified an appeals committee to address complaints when the complainant was dissatisfied with the complaints officer's findings, due to the non-implementation of the local complaints process, there were no records of referrals to the appeals committee. The centre did not maintain a complaints log to record complaints, the outcome of the complaints process or whether or not the complainant was satisfied with the outcome. There was no evidence of a process to oversee the complaints process in order to ensure compliance. There was no signage on clear display identifying… how to make a complaint, the responsible person for dealing with complaints or the appeals process.

The poor quality of the buildings and poor maintenance of many residential centres was a common feature in many of the earlier inspections, and there were challenges

in relation to fire safety. Some providers were failing to uphold residents' rights to live a dignified life, as many residents were not living in clean and homely spaces, as illustrated in this inspection report from 2014:

Significant dampness and inadequate ventilation

The apartment was in need of major renovation, as there was significant evidence of dampness and inadequate ventilation in a number of rooms; for example, the bathroom was extremely damp, and the premises felt cold. Also, the inspector found that there was limited space in the resident's bedroom for storing clothes or equipment.

Poor layout of many premises resulted in crowded, noisy experiences for many residents, as illustrated in this inspection report from 2015:

Constant elevated noise levels

The unsuitable design and layout of the premises also meant that there were nearly constant elevated noise levels. During the time that inspectors were in one unit that accommodated 17 residents, there was no period when the noise levels were not high. There were significant levels of noise from residents shouting and frequently several residents were shouting simultaneously. This was a cause of upset and agitation to other residents who were assessed as requiring a quiet environment. Inspectors also saw evidence of residents being fearful at night-time and choosing to sleep on a couch rather than in their bedroom.

Nonetheless, good residential care for people with disabilities was often being provided in poor premises. This report from a 2014 inspection of a congregated setting illustrates this common finding:

Good care being provided in poor premises

Inspectors found the design and layout of one occupied unit within the designated centre did not meet the residents' needs and the requirements of the regulations… the building is not maintained in good standard of repair… the unit is not homely or decorated to a good standard… parts of the building were not maintained to a good standard of cleanliness such as the laundry area, parts of the communal area and hallways… There was some evidence of good practice in the centre. Residents were familiar with the staff, who in turn were knowledgeable of the residents' health and social care needs. Inspectors found that residents were supported to develop and maintain personal relationships and that families were encouraged and welcomed to be involved in the lives of

residents. The person in charge and staff responded effectively to the communication support needs of residents.

1.3 Time to move on from congregated settings

Our experience has shown that residents who move to the community from institutional-style settings enjoy better lives. One of the biggest challenges to ensuring residents enjoy a good quality of life has been the dominance of so-called 'congregated settings'. These are usually large, institutional-style buildings or poor quality chalet accommodation where large groups of people live together, often not by choice. There can be conflicts of personality between residents, while some live in fear of other residents, and providers sometimes fail to appropriately manage and address such situations. Efforts to 'decongregate' — the process of providers moving residents out of such institutions to live in a house in the community — have stalled in recent years.

There are many reasons for the slow pace of decongregation. For example, the general shortage of housing nationally has limited the options available to providers. Tied to this point is the level of funding available to acquire new premises and staff them according to residents' assessed needs. There is also a reluctance on the part of some providers to decongregate due to the complexity of care required by some residents.

A public outcry followed the broadcasting of an RTÉ television programme in December 2014 on care standards in a designated centre in the West of Ireland.[1] The footage depicted disturbing and abusive practices in one unit of a congregated setting and provided clear evidence of abusive practices being used against adults at risk. We focused on this centre from 2015 to 2017, and we challenged the persistent non-compliance and lack of progress until the provider had taken effective measures. As a result, many of the residents moved to smaller community-based accommodation and our subsequent inspections of those centres found a significant improvement in the safety and quality of life for residents.[2]

The Chief Inspector within HIQA has continued to engage with providers of residential services in congregated settings and, as a result of regulation, providers have improved the quality of service for residents in these centres over the course of the past 10 years. However, we have also found that there continues to be higher

[1] RTÉ audio version of this programme is available on RTE Archives.

[2] Overview of HIQA's monitoring activity in Áras Attracta 2015-2017: November 2017.

levels of non-compliance and a greater risk to the safety and wellbeing of people with disabilities who continue to live in these environments.

While it is national policy to decongregate, there is no legal requirement to do so. This is despite decongregation being about more than moving to a new home in the community but also a question of respecting and promoting residents' rights, as set out in regulations and in the United Nations Declaration on the Rights of People with Disabilities (UNDRPD). Those rights include the right to move to smaller settings with your friends or a group of friends, who have lived together in a congregated setting, and to view and experience the new community setting before moving there. A number of providers have striven to achieve this, but a number of anticipated moves have been hit with delays while residents continued to live in poorly maintained congregated settings. This is discussed further in Chapter 9.

1.4 Conclusion to setting the scene

A significant number of designated centres were not fit for purpose nor providing a good quality of life for residents when regulation began in late 2013. Our task, as the regulator, was to identify each of these designated centres, conduct intensive monitoring and engage with residents and registered providers to improve their services, and the vast majority have done so over the intervening decade. Where registered providers were not capable of improvement, we took action to safeguard residents and remove the registered provider from the register (see Chapter 4 for information on our enforcement actions).

Regulation meant that registered providers were faced with many challenges in order to ensure that they were compliant with the regulations and standards. Over the past decade, more providers have embarked on a new culture of placing the resident front and centre of everything they do. As the regulator, we have also evolved our approach as we have learned about the most effective way to ensure residents receive good quality care. This includes giving more prominence to the views and experiences of residents in our published inspection reports, which will be discussed further in Chapter 3 of this report.

Meanwhile, over the course of 10 years of regulation covered by this report, there has been a significant increase in the number of smaller designated centres for people with disabilities, in response to the ongoing need for residential services for people in the community as well as providers moving or planning to move residents from large congregated settings to the community. There has also been an overall steady increase in the number of residential places available for people with disabilities (discussed further in Chapter 4). As the sector continues to develop and grow, planning will be required to ensure resources are in place to maintain the ongoing effective regulation of services.

Chapter 2: Formation of HIQA

The purpose of regulation is to ensure that the rights of people with disabilities living in designated centres are upheld, that they have a good quality of life and a safe place to live and that those charged with providing the service are held to account for the quality and safety of that service.

Registered providers, the State and the regulator have a common goal but different roles and challenges. For example, providers are responsible for delivering person-centred, human rights-based care and support in a safe, homely environment. The State aims to achieve best outcomes for residents while ensuring good value for public money. The State and its Government departments also set policy direction on behalf of the State to ensure the rights of people with disabilities are upheld.

The job of the Chief Inspector in HIQA is to provide an independent viewpoint of these services, and to ensure legal minimum requirements — as set out by the State in legislation and regulations — are met with a view to providing safe and good quality care and support. The regulator also encourages providers to move beyond the minimum regulatory requirements and promotes ongoing quality improvement in care and support through developing and monitoring national standards.

2.1 Establishment of HIQA

The first key step to regulating residential centres for people with disabilities was the establishment of the Health Information and Quality Authority (HIQA) on 15 May 2007 as part of the Government's overall Health Reform Programme. Reporting directly to the Minister for Health, HIQA's role is to promote safety and quality in health and personal social services for the benefit of the health and welfare of the public. The key drivers of quality are all contained within the functions of HIQA, which are set out in the Health Act 2007 (as amended).[3]

2.1.1 The Chief Inspector of Social Services

The former Social Services Inspectorate (SSI), interim Health Information and Quality Authority and the former Irish Health Services Accreditation Board (IHSAB) were all integrated into HIQA on its establishment in May 2007, with staff from the three bodies transferring across. Up to that point, the Chief Inspector of the non-statutory SSI had inspected all children's residential centres, and had conducted pilot inspections of foster care services.[4] The HSE also had a role in inspecting private nursing homes, but there were no regulations or independent oversight of residential

[3] Number 23 of 2007: Health Act 2007 Revised: Updated to 28 February 2024. Health (Amendment) Act 2016. Dublin: Government Publication Office 2017.

[4] SSI Annual Report 2004. Available online from Lenus.ie.

services for people with disabilities. This SSI role and HSE role was given expanded functions and powers in the establishment of the statutory Office of the Chief Inspector of Social Services within HIQA.

The first Chief Inspector of Social Services was appointed in July 2007[5] and took up position on 1 October 2007.[6] In November 2007, HIQA established a standards advisory group to develop standards for residential centres for people with disabilities. Throughout 2008, HIQA inspected residential care services for children and other services for children in care while preparing for the regulation of residential services for older people and people with disabilities.[7]

2.2 Planning for regulation

Planning by HIQA for the regulation of designated centres for people with disabilities began in 2008 amid widespread demands for improved oversight in the sector following a number of scandals. Of particular concern were the very poor living conditions for people with disabilities living in congregated settings. As the sector remained unregulated, HIQA began to receive concerns from members of the public about the quality of some residential disability services.[8]

Throughout 2012, HIQA worked closely with the Department of Health, the then Department of Children and Youth Affairs and the HSE in identifying the number, scope and nature of residential services provided to people with disabilities in Ireland. Other preparatory work in 2012 included workforce planning and developing methodology to undertake the regulatory work.[9]

As we planned for the commencement of regulation, we worked with self-advocacy and advocacy groups across the country. One of the challenges that they put to us was to ensure that the voice of the residents was reflected in our inspection reports. The voice and views of residents and their families were subsequently captured in our inspection reports, but were significantly enhanced from 2018 onwards. In 2012, we set up a Provider Representative Forum as a means to engage with registered providers and share information. We also hosted four packed information meetings on the regulatory process for prospective service providers during May 2013 in Sligo, Dublin (two meetings) and Cork, attended by hundreds of managers and providers

[5] HIQA News Updates. 23 July, 2007. Chief Inspector of Social Services appointed by Health Information and Quality Authority.

[6] 2007 Annual Report Health Information and Quality Authority.

[7] 2008 Annual Report Health Information and Quality Authority.

[8] HIQA Annual Reports for 2010, 2011 and 2012, all available on www.hiqa.ie.

[9] 2012 Annual Report Health Information and Quality Authority.

of services in the disability sector. We also met advocates of people using these services in advance of regulating the sector.[10]

The commencement of regulation in a new setting also requires a whole new suite of tools, processes and documents. These were necessary in order to effectively manage all of the regulatory processes that were required under the Health Act 2007 and the associated regulations. Our teams worked hard to develop these internal systems so that we had the capacity to manage the additional workload. This included the development of a new IT system (PRISM) to manage these processes.

2.3 National standards for disability services

The first *National Quality Standards for Residential Care Settings for People with Disabilities* were published in May 2009. These standards outlined what a person with a disability, their family and the public could expect from such services and what was expected of registered providers of the services.[11] We reviewed these standards in 2012, and amended draft standards were launched for public consultation in October 2012.

Over 100 submissions to the public consultation were received, and the resulting revised *National Standards for Residential Services for Children and Adults with Disabilities* were launched on 14 May 2013.[12] The national standards apply to residential services and residential respite services provided to children and adults with a disability by the HSE or by HSE-funded registered providers in the voluntary sector, and a number of private registered providers.

2.4 Regulation of residential centres begins

By mid-2013, HIQA had been sanctioned to recruit additional inspectors and other regulatory staff. In November 2013, we began to regulate residential services for people with disabilities. This was the first time that such services had ever been independently regulated.[13] Once regulation started, the Chief Inspector wrote to providers to ask them to formally notify us of their designated centres, and advise of their bed capacity.[14] When regulation commenced on 1 November 2013, providers had reported that there were 920 designated centres providing around 8,000

[10] HIQA-News-Issue-4.pdf.

[11] 2009 Annual Report Health Information and Quality Authority.

[12] HIQA-News-Issue-3.pdf.

[13] Five years of regulation in designated centres for people with a disability: July 2019. Dublin: HIQA; 2019.

[14] HIQA-News-Issue-5.pdf.

residential places. Initially, our focus was on the risk to residents and safeguarding (see risk-rating of concerns in Chapter 4), and giving time for providers to learn about regulation.

2.5 Two-year extension for registration deadline

It was originally intended that all designated centres for people with disabilities would be registered by the Chief Inspector within three years of commencement of regulation, that is to say, by 31 October 2016. As we progressed through the first two to three years of regulation, it became clear that this deadline would not be met. This was due to our assessment that a significant number of designated centres could not be registered due to their poor compliance with regulations.

We engaged with Government departments to relay our concerns in this regard and the Government decided that the Act would be amended and the deadline extended to 31 October 2018, thereby allowing providers up to five years in which to achieve their first registration; this deadline was subsequently met.

Chapter 3: The voice of the resident

This chapter of this report focuses on the theme of 'voice of the resident' and describes how we, as a regulator, have adapted our approach to give more prominence to people's voices in our inspection reports and our general work.

3.1 United Nations Convention on the Rights of Persons with Disabilities and safeguarding

Our focus on the voice of the resident promotes key aspects of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and several articles under this convention. These include:

- Article 5 — Equality and non-discrimination
- Article 8 — Awareness-raising
- Article 12 — Equal recognition before the law
- Article 21 — Freedom of expression and opinion, and access to information
- Article 22 — Respect for privacy
- Article 25 — Health.

Ensuring that the voice of the resident is central to the delivery of services recognises that they are the experts 'on their own experiences, needs and wishes'.

3.2 Seeking out the voice of residents

Meeting people who use services is a critically important aspect of our inspection methodology. Hearing from residents and understanding their lived experiences are both essential in determining how their rights are respected and ensuring that they are supported to live a fulfilling life. Our inspectors spend time meeting residents while on inspection, and we use the information they give us to inform our inspection findings. In our experience, this engagement supports quality improvement in designated centres.[15]

In the early years of regulation, while we met and engaged with residents on inspection, our reports did not place enough emphasis on lived experiences. The Chief Inspector responded to calls to place more emphasis on the voice of residents and what it is like to live in a centre, which are now explicitly covered in the opening section of all inspection reports. Examples of this are shown in the next table:

[15] Chief Inspector speaking at the Oireachtas Joint Committee on Disability Matters, 8 November 2023.

What residents told us and what inspectors observed — 2023

Overall, the resident told the inspector that they enjoyed living in the centre; however, there were a few matters that were impacting on their lived experience. The resident advised the inspector that there had been a lot of change in the centre. The resident spoke about the amount of different and unfamiliar staff working in the centre and expressed how, at times, it had raised their anxieties. They said that while they enjoyed spending time and going for coffee with familiar staff, some of whom were agency staff, they were at times concerned about the care and support provided to them by unfamiliar staff.

What residents told us and what inspectors observed — 2022

The inspector spent time talking with the resident while playing a game of dominoes. They told the inspector that they were very happy living in the centre and enjoyed the space and peace of their environment. They said that they felt safe and could raise any concerns with the team leader, person in charge, or chief executive officer of the service. During the inspection, the resident rang the chief executive officer to inform them of the inspection. The resident spoke about a recent foreign holiday, and told the inspector that they were very close to their family and visited them often.

Some people do not use verbal communication and they communicate in other ways. If residents cannot or do not wish to talk with us, we will spend time with them observing their daily routine, interactions with staff and others living in or visiting the centre to understand how this impacts on their quality of life. Where possible, we will also speak with their relatives or advocates. As mentioned above, in recent years, we changed our inspection reports to include a specific section on what residents tell us about their service. This enables us to describe what it is like to live in a designated centre from the experiences of people living there, how they are integrated into the community and how they are supported or not to do what they want to do, to access education and how that is supported or not supported by the registered provider.[16] For instance, in these inspections from 2024 and 2021:

[16] Ibid.

Giving voice to residents — February 2024

One resident liked a specific routine that they kept to each day. On the morning of the inspection, they had gone on a walk and to purchase items in the shop. This was a good example to show how this resident was being supported to integrate into their local community and increase their independence. For example, the resident now went into the shop and chose the item they wanted, brought it to the counter and paid for the item themselves.

Giving voice to residents — March 2024

The residents are within walking distance of the butchers, pharmacy, shops and other amenities. A staff member who knows the residents well informed the inspector that all of the people in the local shops know the residents by their name. As a team, the staff and residents had also done some fund raising for a recognised charity and had raised a large amount of money doing this.

Giving voice to residents — April 2021

Prior to the pandemic one resident had secured a part time job in a local supermarket for which they received a weekly wage. This enabled them to have some additional income and also get to know new people in their community. Other residents had been involved in local retirement groups or swimming clubs.

The overall feedback from residents to us is that they feel comfortable talking to inspectors and think that our inspections are a good thing. In some cases, they say their feedback to providers has not resulted in any improvements and we then follow up as to why they are not changing. We are very careful when speaking with residents while out on inspection in centres. For example, in very small centres, it can be difficult to find a private place in which to talk with residents. Our inspectors are very keen to talk. If a resident does not want to talk with us, we will respect that and not do so, but then we will observe interactions between residents and staff and interactions among residents. This is because not everybody gets on with everyone they live with and this can have a significant impact on the quality of life in centres.[17]

3.3 Engagement with residents outside the inspection process

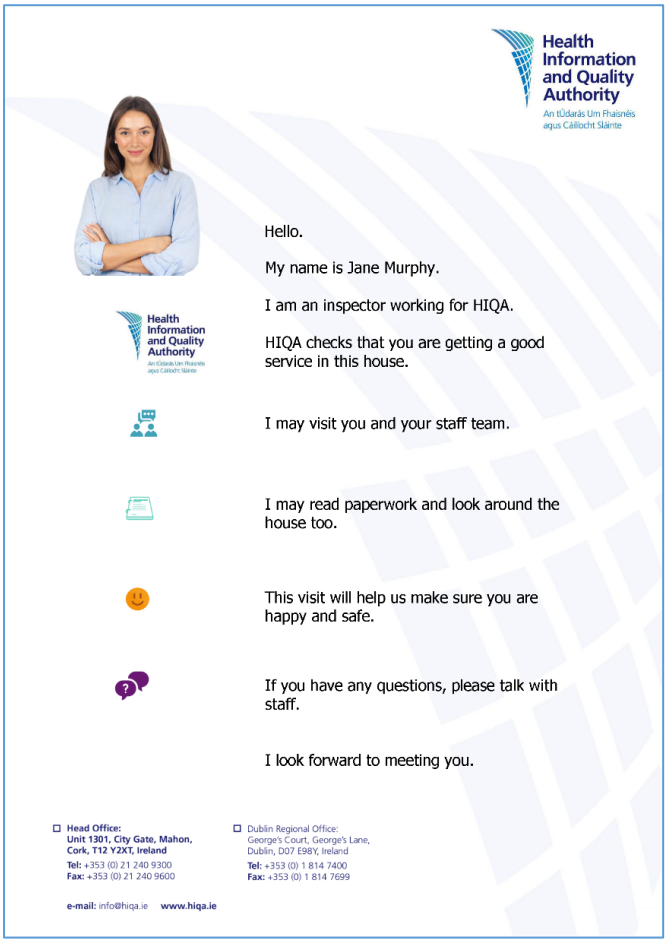
Meeting with residents during inspections is important, but we also value opportunities for engaging with residents outside of an inspection environment.

[17] Chief Inspector speaking at the Oireachtas Joint Committee on Disability Matters, 27 October 2022.

From 2012, we have had regular meetings with residents' representatives and advocacy groups to hear directly from residents about what is important to them in their centres and to listen to them about their experience of inspection. People with disabilities who attended those meetings suggested to us that it would be better to meet residents in their own environment where they feel comfortable and also where they have their supports.

From 2018, we started to identify and communicate with local resident advocacy groups across the country and, where those groups were happy to meet us, we began attending a selection of these groups each year. These forums are hugely important to us and have provided an opportunity for residents to meet with us and share their views outside of the inspection process. In response to the feedback from residents, we also sought to ensure that their views are shared more widely and to date, we have published three reports of the outcome of these meetings on our website: in December 2020, October 2022 and June 2024.

Following each series of meetings with resident groups, we seek to identify actions that we can take in response to the views of residents. For example, residents said that they would like us to provide a document to residents at the start of each inspection that would introduce the inspector and explain the inspection process. In 2022, the Chief Inspector introduced a 'Nice to Meet You' document which is distributed to designated centres before announced inspections. In addition, on unannounced inspections, the inspector gives this document to residents at the start of the inspection when they are introducing themselves. Residents and their advocacy groups have reported that they like the 'Nice to Meet You' document and find it very helpful.[18]


Health Information and Quality Authority
An tÚdarás Um Fhaisnéis agus Cáilíocht Sláinte

Hello.

My name is Jane Murphy.

I am an inspector working for HIQA.

HIQA checks that you are getting a good service in this house.

I may visit you and your staff team.

I may read paperwork and look around the house too.

This visit will help us make sure you are happy and safe.

If you have any questions, please talk with staff.

I look forward to meeting you.

Head Office:
Unit 1301, City Gate, Mahon,
Cork, T12 Y2XT, Ireland
Tel: +353 (0) 21 240 9300
Fax: +353 (0) 21 240 9600

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Dublin, D07 E98Y, Ireland
Tel: +353 (0) 1 814 7400
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e-mail: info@hiqa.ie www.hiqa.ie

[18] Annual overview report on the inspection and regulation of disability services in 2022.

The feedback we get from residents tells us about what is important in their lives. For example, residents told us about how their quality of life improved when they moved from congregated settings to small, local, personalised homes in the community.[19] In an earlier residents' forum report, some residents had told us about how they found it difficult to have their voice heard when they lived in a larger setting.[20] Listening to their views ensures that we can continue to focus on the requirement for providers to uphold the rights of residents and that the choices and preferences of people with disabilities are respected.[21] Residents also tell us about their views of the inspection process and this information is used in discussions with inspectors to ensure that they use this information when they are inspecting centres.

During 2022, 88 residents participated in 15 face-to-face resident forums. In 2023, a survey was distributed to a sample group of residents to gain insight into their views on the residents' forums and the resulting reports. Quite a few residents highlighted to us that management had not given them copies of the previous reports about residents' feedback that we had published. They said that they were not always aware of these reports or the actions we have taken in response to feedback. This was very disappointing; therefore, we would encourage all providers to share the findings of these reports in a way that aligns with residents' communication preferences and support needs.[22]

3.4 Complaints management

Complaints are one way for residents to make their voice heard if they are not happy about something. A good provider is responsive to complaints and sees them as a learning opportunity. We can follow through in respect of the provider's complaints arrangements and how it encourages people to express their views through complaints. We also consider the follow-up to complaints and sometimes check in with the person making the complaint afterwards to see whether they were satisfied with how the provider responded. Here, we present an example of both poor practice with respect to complaints management and how it can be done well:

[19] HIQA. Resident Forums in Centres for People with Disabilities 2021.

[20] HIQA. Disability Services Resident Forum Meetings: December 2020.

[21] Chief Inspector speaking at the Oireachtas Joint Committee on Disability Matters, 27 October 2022.

[22] Resident Forums in Centres for People with Disabilities 2022–2023. Dublin: HIQA; 2024.

Example of poor complaints practice (2022 inspection)

The provider advised that it had retrospectively logged issues raised as complaints and had committed to logging any future complaints (including those made verbally) and forwarding them to the Complaints Coordinator. It was also referenced in an April 2021 report written following an unannounced visit to the centre that management staff had assured the provider's representatives that they would process recently made verbal complaints in keeping with the provider's complaints policy. The inspector asked to see the complaints log for the centre. Only one complaint had been documented and was dated September 2020. When asked if there had been any more recent complaints, management advised that there had been but that these had not been documented. They were, therefore, not subject to the provider's complaints policy. It was evident that the provider's complaints policy was not being implemented in this centre.

Example of a good complaints system in place (2023 inspection)

The inspector found that the provider had systems in place for a complaints process. An easy-to-read complaints procedure was available for residents and a flow chart was on display for residents. Residents had access if needed to an appeals process. Following a review of the complaints log, there was evidence of the centre receiving no complaint in the previous 12 months. The inspector spoke to the person participating in management, team leader and staff on the day who all displayed their knowledge on the process and documentation they would complete if they received a complaint. Staff highlighted they would support residents to make a complaint regarding issues affecting them if and when needed. There were no open complaints on the day of the inspection.

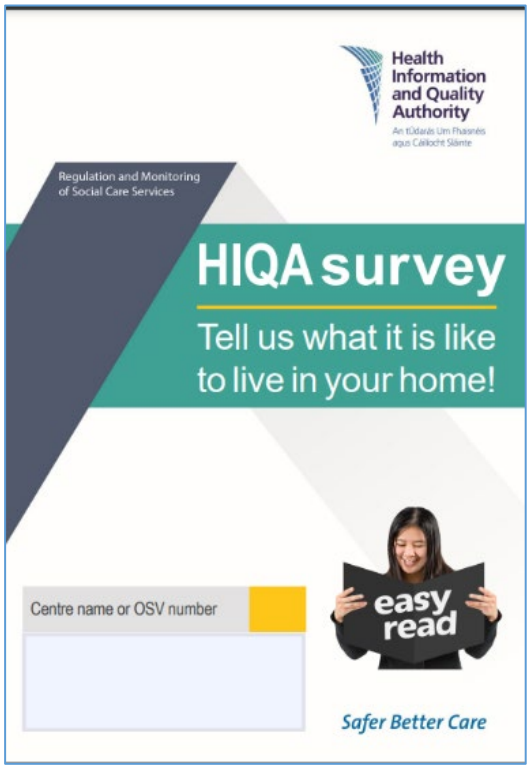
Poor providers do not respond to complaints proactively. We have seen situations where complaints were not recorded, where there has been a dismissive attitude, and where providers cannot demonstrate that they have gone back afterwards to check whether the person who made the complaint was satisfied. In those situations, we will assess compliance with the regulations around complaints, and will require the provider to improve those arrangements where required.

3.5 Working with residents to develop a feedback questionnaire

Residents' questionnaires (also called residents' surveys) are sent out to providers in advance of announced inspections to allow residents to provide feedback on what it is like to live in a designated centre. Residents, relatives, family, advocates or people who support residents can also complete the survey at any time outside of the inspection process and send it to us. The survey is available on www.hiqa.ie.

In late 2022 and early 2023, the Chief Inspector worked with residents of designated centres for people with disabilities to help us update our residents' questionnaire. The aim was to make them more user-friendly and make it easier for residents to give us feedback as independently as possible.[23] We developed a draft of a new version of the survey and trialled it on announced inspections, and sent it to some advocacy groups for feedback. Some inspectors also showed it to residents and staff while on unannounced inspections.

We made a lot of changes to the questionnaire in response to feedback from residents. For example, instead of the statement 'this is a nice place to live', it was suggested that we ask a question such as, 'is this a nice place to live?' We also included images and different colours for the questionnaire. We continue to welcome feedback on the questionnaire from residents and relatives.



The final survey was published in October 2023, and reviewed again in mid-2024. In early 2024, following further feedback from residents, we began work on the design of a second style of residents' questionnaire to provide choice to residents on the format that they prefer to use. At the time of writing, work on this is ongoing.

[23] Chief Inspector at the Joint Committee on Disability Matters, 27 October 2022.

Chapter 4: Emerging trends over the 10 years of regulation

This chapter sets out some of the key trends and statistics that illustrate how the disability sector and the Chief Inspector, as regulator, have evolved in the past decade. It shows that the number of designated centres is projected to have doubled by 2028 compared to the first full year of regulation in 2014, and that the number of residential placements is increasing steadily. However, while there are an increased number of smaller designated centres in recent years, many of these are still on the campuses of large institutional settings, rather than residents truly transitioning to live in the community. Nonetheless, the data shows the level of activity associated with regulation over the past decade, including: almost 9,500 inspections of services between 2014 and 2023; 434 restrictive conditions of registration between 2016 and 2023; an estimated one urgent compliance plan being issued to providers each fortnight; and the Chief Inspector cancelling the registration of 15 centres between 2013 and 2023 on foot of concerns about residents' safety and welfare. More detailed compliance data for 2023 is available in Appendix 1.

4.1 Number of designated centres

Designated centres is the term used in the Health Act 2007 (as amended) (the Act) for residential services that meet the criteria set out in the Act. There are three types of designated centre for people with disabilities: adults; children; and mixed (accommodating both adults and children). Mixed centres are mostly respite centres where there are separate respite breaks for children and for adults. Children and adults are not usually accommodated together unless there are specific reasons for it, such as children transitioning to adulthood (where they may wish to continue living with peers) or when a family unit is being accommodated together in a service.

The number of designated centres providing residential and respite services to people with disabilities has increased steadily since the commencement of regulation by the Chief Inspector in 2013 (see Figure 1 on the following page). The steady rise in the number of designated centres has been driven primarily by three factors: responding to the emergency accommodation requirements of people with disabilities; the transition of people from congregated settings to smaller, community-based settings; and an increase in the number of individualised services for some people who find it difficult to share a living environment.

There has been a slow but ongoing process of decongregation — transitioning residents from large, campus-based settings into smaller living arrangements in the community (see section on decongregation later in this chapter).

For example, where one congregated setting may have provided services for 20 residents, the creation of four 5-bed units means an increase in the overall number of centres. Large group homes have also been becoming smaller in nature and accommodating smaller groups of residents (two or three residents).

There is clearly a trend towards providing individualised services for some people whose care needs may be high or where the person prefers to live alone. This, in turn, also increases the number of designated centres nationally. Here, we present an example from an inspection of positive outcomes for people who have moved from a congregated setting into a smaller community home.

Positive outcomes for people who move to the community

The residents moved to the centre in November 2023 having previously lived together in a campus-based centre operated by the provider, and told the inspector that they were happier living in their new home. They described the premises as being "nice" with "beautiful" bedrooms that had enough space and comfortable furniture. They told the inspector about how they were getting to know their new community; for example, they had visited the local shops and salons. There was a vehicle available to them, and they said that they could "go anywhere" on it. They also enjoyed in-house leisure activities, such as art, knitting, and watching television. It was clear that residents were supported to be active participants in the running of the centre and be involved in their community.

Figure 1 – Number of designated centres from 2014–2023

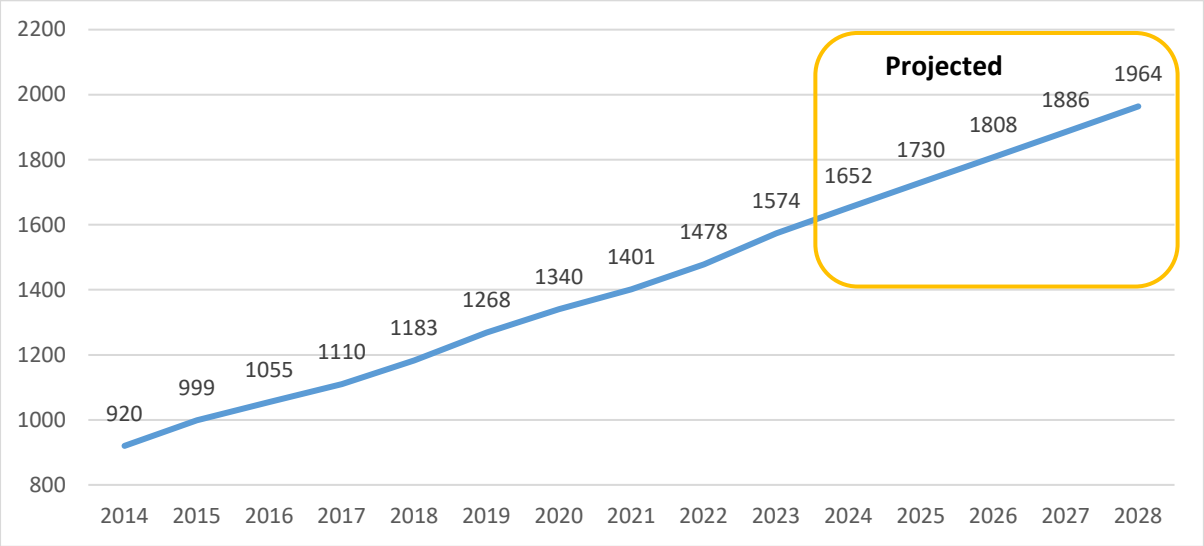


Figure 1 above illustrates the upward trend in the number of designated centres nationally. The graph also includes a projection, based on current growth rates, for the number of designated centres out to 2028. The projection suggests that the

number will have more than doubled during the period 2014–2028. This places additional pressure on the resources of HIQA as the regulator. Greater numbers of designated centres requires resource planning for the inspection and monitoring of services, and we will be working closely with the Department of Health and the Department of Children, Equality, Disability, Integration and Youth to ensure that there is capacity to continue to effectively regulate all designated centres.

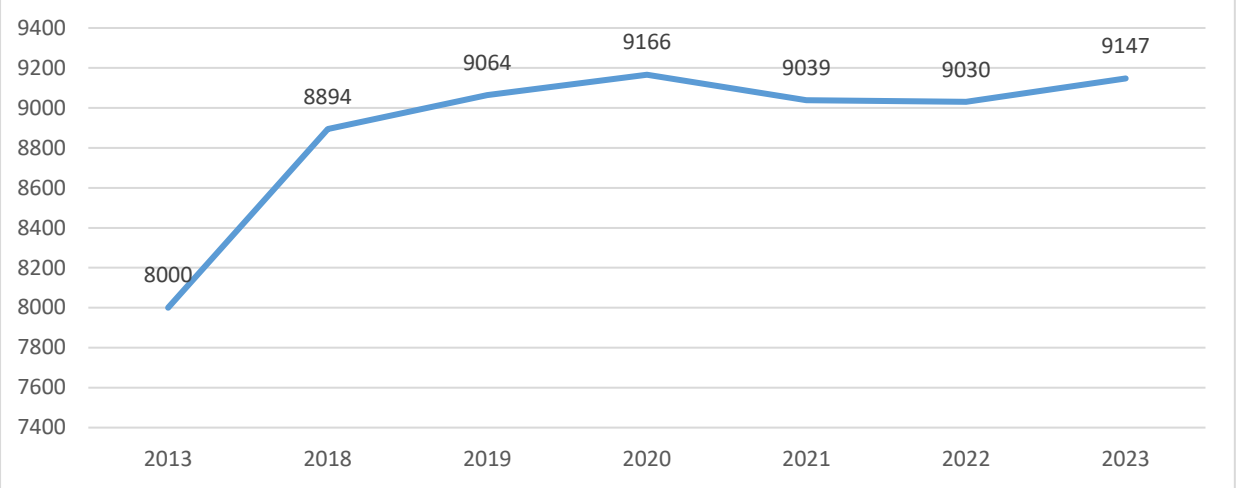
4.2 Number of placements nationally

The number of designated centres has been increasing consistently in recent years, as shown above, and there has been a steady increase in the numbers of residential placements available for people with disabilities — with the exception of the COVID-19 pandemic when many additional beds were temporarily added to the register in order to provide isolation and treatment spaces for residents.

The verified number of residential places could only be confirmed with the completion of the first cycle of registration in 2018, when all of the centres notified to the Chief Inspector as designated centres on 1 November 2013 were registered, along with the additional centres that were registered during that time. On 1 November 2013, providers self-reported around 8,000 residential places in 920 designated centres. By 31 October 2018, there were 8,894 verified residential places in 1,183 registered designated centres for adults and children with disabilities.

During the early outbreak of the pandemic, in 2020, a range of additional centres and residential places were registered to provide isolation and treatment facilities for people living in designated centres who had contracted COVID-19. As the period of pandemic progressed and the sector put other measures in place to respond to infection, those additional centres and residential places were slowly removed from the register. This can be seen in Figure 2 below.

*Figure 2 – Number of placements in designated centres from 2013–2023**



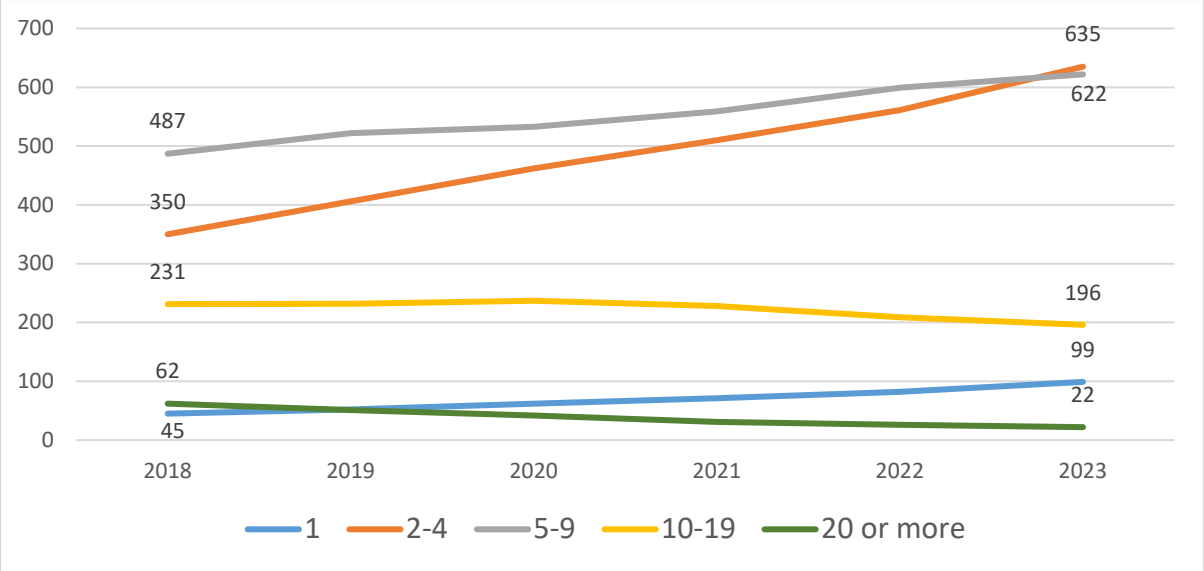
* Data from 2013 until 2018 represents a combination of both unverified self-reported placements by providers and registered places as centres were being registered by the Chief Inspector. Data from 2018 onwards represents validated data by the Chief Inspector once all centres had been registered. A slight decrease in placements in 2021 and 2022 was as a result of additional places created due to the pandemic being removed.

4.3 Changes in the size of designated centres

The welcome move towards providing services in smaller, community-based designated centres for people with disabilities is partly borne out by the changes observed in size of centres over time. The number of larger designated centres providing care and support to 20 or more residents has dropped by almost two-thirds (nearly 65%) between 2018 and 2023 (see Figure 3 below); the number of designated centres that provide between 10–19 beds has also dropped in this time period.

However, many of these changes happened because providers of larger centres started to divide them into smaller centres on the same campus or site — to both improve oversight as many had previously been large and unwieldly, and to prepare for smaller groups of people moving to the community. Therefore, these figures alone are not a wholly reflective picture of decongregation as residents continue to live in campus-based settings, albeit in smaller housing units. In addition, providers often register a number of small, community-based houses within a close geographic region as one centre.

*Figure 3 – Number of designated centres according to categories of bed number from 2018-2023**



* The availability of bed-number data prior to 2018 is limited as only centres that had been fully registered were counted. In 2018, the Chief Inspector completed the initial registration of all designated centres for people with disabilities. As such, reporting data before 2018 could be misleading.

The decline in larger designated centres during the period 2018–2023 is coupled with a rise in the number of smaller registered centres. For example, the number of designated centres providing care to one person has more than doubled in the period. Similar increases are evident in the number of designated centres with two to four registered residential places and five to nine registered residential places.

4.4 The process of decongregation

It is national policy for decongregation of social care services — since the publication of *Time to Move on from Congregated Settings* in 2011[24] — to cease the practice of providing services to people with disabilities in large, campus-style settings. Given the positive impact on the lives of residents, HIQA broadly supports the national policy for transitioning people with disabilities from congregated settings to more appropriate community-based places to live, although further work is required to ensure that this policy is implemented in an effective and timely manner.[25]

Such settings are institutional in nature and not capable of providing the best outcomes for those who live there.[26] The national policy sets out a vision that all housing arrangements for people with disabilities should be in 'ordinary neighbourhoods in the community' with individualised supports made available. These community-based settings were to be of a maximum of four beds. While there has been some progress towards this goal, the target for completion (2018) has long passed and by the end of 2023, almost 25% of all people with disabilities living in designated residential centres were still living in congregated settings.

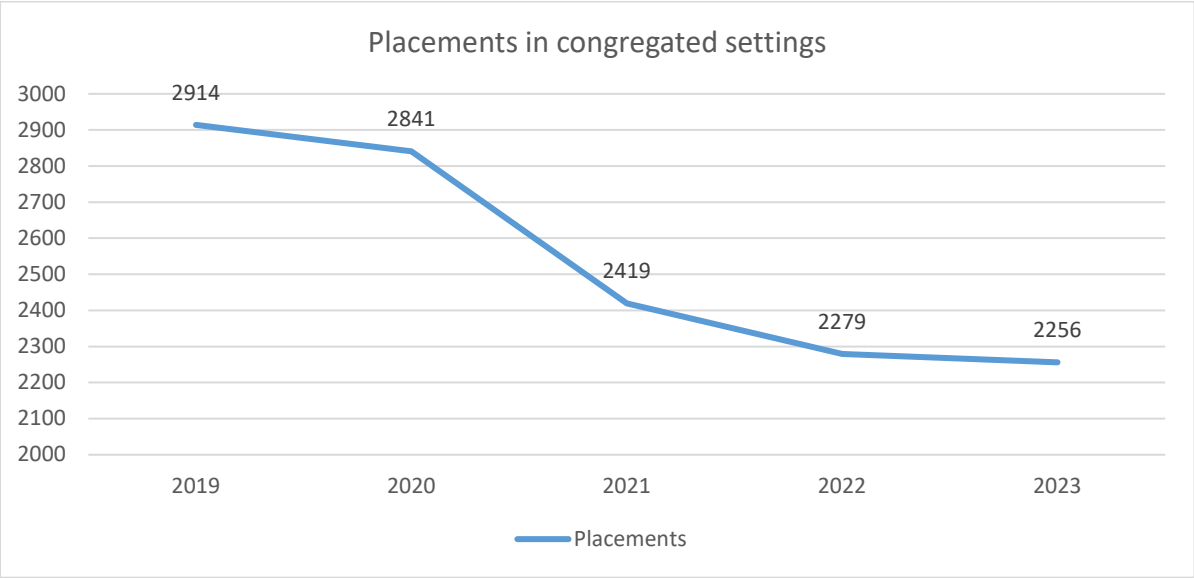
As the regulator, we have in recent years closely monitored the number of congregated settings. While there is no legal requirement for the transition of residents from congregated settings into the community, we are keen to see this happen as swiftly as possible due to the improved outcomes people experience from living in the community. Our information (Figure 4) shows that the number of people living in congregated settings (defined as providing 10 or more beds or based in a campus-style setting) has been decreasing slowly in recent years.

[24] Health Service Executive. Time to Move On from Congregated Settings: A Strategy for Community Inclusion. Dublin: Health Service Executive; 2011.

[25] Chief Inspector speaking at the Oireachtas Joint Committee on Disability Matters, 27 October 2022.

[26] Health Service Executive. Time to Move On from Congregated Settings.

*Figure 4 – Number of placements in congregated settings 2019–2023**



* Data is only available for the period 2019–2023.

According to the *Time to Move on from Congregated Settings* strategy, there were an estimated 4,000 placements in congregated settings in 2011. Our most recent number of registered residential places (2,256) suggests that the number has not even halved since the publication of the strategy in 2011 up to 2023. If this pace of change continues, it will be a considerable period of time before congregated settings are phased out of the system for supporting people with disabilities in Ireland. Our data shows a recent slowdown in the move from congregated settings which is concerning. With congregated settings, residents experience poorer outcomes due to settings that are outmoded and reminiscent of institutions rather than homes.[27]

It should be acknowledged that there is some resistance to the closure of some congregated settings in communities across the country from providers and in some cases residents and their families. It is understandable that there would be reluctance on the part of residents or families to move out of a place that they may have called home for a considerable period of time. Communities may also fear the loss of support services in their locality. Nevertheless, our inspection findings have consistently found that transitioning from congregated settings into designated centres in the community is a necessary step towards improving outcomes and quality of life for people and modernising the country's services. Our experience of working with residents and registered providers in this transition has produced

[27] Chief Inspector addressing the Oireachtas Joint Committee on Disability Matters, 31 March 2022.

countless examples of the positive impact on people who move, including the example illustrated below and reported in the HIQA newsletter in early 2024.[28]

Enhanced quality of life for residents who moved to the community

In 2023, we worked closely with COPE Foundation to support a group of residents to move from living in a congregated setting to their new, smaller homes in the community in time for Christmas 2023.

In March 2021, COPE Foundation took over the operations of a previously poorly-run congregated setting. They began a process of engaging with the residents and worked to improve their current living environment while also identifying new homes in the community.

During the transition period, residents told inspectors of their excitement at the plans to move to their new homes and how they were involved in the arrangements for the move.

At the request of residents, COPE Foundation asked that the new houses be registered in time so that they could move in before Christmas. As the registered provider had put all of the appropriate arrangements in place to ensure that the rights of residents would be upheld in their new homes and because of the quality of engagement with residents in planning for the move, the Chief Inspector within HIQA was able to facilitate a timely registration of the new houses. As a result, residents began moving before Christmas.

The provider informed us that the residents were very happy with their new homes and that they are looking forward to welcoming the inspectors and showing them around in the near future.

As well as the examples found by inspectors, other examples have been provided by the HSE which has produced videos describing the positive outcomes for residents that have moved from congregated settings such as Áras Attracta in Mayo and St. Raphael's in Cork into homes in the community. The videos are available on the HSE's YouTube page.

4.5 Registered providers of designated centres

All designated centres are operated by organisations known as registered providers. Registered providers are legally responsible for the care and support of people with

[28] HIQA News, 21 February 2024, Issue 59. Residents of disability centre move to new homes.

disabilities in designated centres,[29] including areas such as staffing and governance. As of the end of 2023, there were 90 registered providers of designated centres. The largest registered provider (Brothers of Charity) operated 194 designated centres whereas at the smaller end of the scale there were 20 registered providers that operated only one designated centre each. Table 1 (below) describes the 10 largest registered providers in the country and the number of designated centres that they operated between 2018 and 2023.

Table 1 – Ten largest registered providers and number of designated centres between 2018 and 2023

Registered provider	2018	2019	2020	2021	2022	2023
Brothers of Charity	152	166	175	182	191	194
Health Service Executive (HSE)	122	138	142	152	159	164
St John of God Community Services	86	91	93	95	100	105
Avista (formerly Daughters of Charity)	87	89	94	95	97	100
Muiríosa Foundation	68	74	83	84	85	92
Nua Healthcare Services	40	48	56	65	71	79
St Michael's House	76	77	78	78	77	77
The Rehab Group	55	61	63	62	65	68
COPE Foundation	39	40	42	44	43	47
Western Care Association	35	35	35	35	35	44
Total designated centres	**760**	**819**	**861**	**892**	**923**	**970**

As Table 1 demonstrates, the top 10 largest providers of designated centres for people with disabilities have collectively increased the number of centres by almost 25% (or one in four centres) over the six-year period.

[29] Chapter 2, page 8, Regulation Handbook. Available online from: https://www.hiqa.ie/sites/default/files/2019-10/Regulation-Handbook.pdf

According to internal research carried out by HIQA, there were 26 for-profit registered providers of disability services at the end of 2023 (as measured by the number of registered providers that did not have registered charity numbers). The provision of care services on a for-profit basis is not a new phenomenon in Ireland — the majority of nursing homes in the country are operated on this model. It is, however, a newer feature in the disability services sector.

For the purposes of regulation, the Chief Inspector does not distinguish between for-profit, not-for-profit, voluntary, community or statutory providers and their responsibility to provide safe and good quality care. The most important consideration regardless of the provider entity is their delivery of good quality care and support to people with disabilities that upholds their rights and that providers have a good level of compliance with regulations and national standards. Our findings over the past decade tell us that many providers across all provider entity types have delivered both good and poor quality services.

4.6 Inspection activity

4.6.1 Introduction to inspection process

All inspectors of social services have the authority to enter designated centres, speak with residents and staff, observe care and review documentation. Nonetheless, we are conscious that a designated centre is a person's home and that while inspecting we are visitors in that home. We take a risk-based approach to regulation. Therefore, we will carry out more inspections in those centres which are demonstrating higher levels of repeated non-compliance with regulations and standards, or where we may receive information from the public which gives rise to a significant concern about the safety of a service.

Inspections are probably the most recognised means by which quality in designated centres is measured. Inspections provide a way to:

- assess compliance with regulations and or national standards at a point in time
- give a voice to residents or children about the experience of living in a designated centre
- observe life in the centre and the routine in the centre, and to speak with residents, families, advocates, staff members and others
- inform the public about the quality of service being provided.

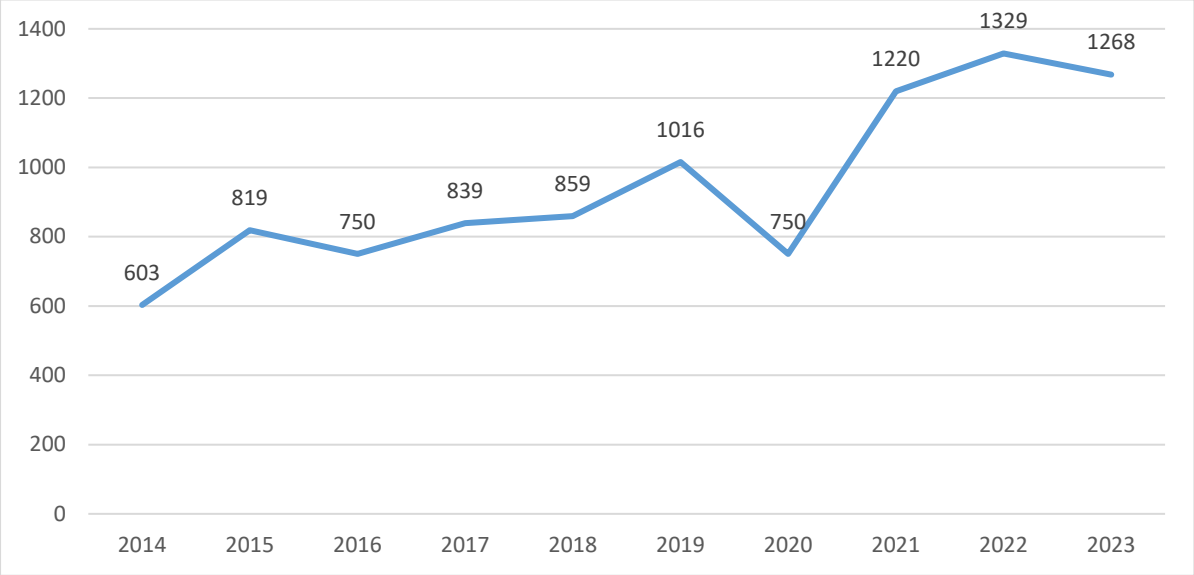
Inspections typically take one or two days to complete. Inspectors review all of the information we have about a centre and identify the regulations they wish to assess in advance of an inspection and then gather evidence throughout the course of the inspection to determine the level of compliance with each identified regulation.

During an inspection, inspectors may also decide to add other regulations that they wish to assess based on information found during the inspection.

4.6.2 Inspection activity since regulation began

Thousands of inspections have been conducted since the introduction of regulation in November 2013. The focus in the early stages of regulation was to get to know the designated centres and focus on those centres that were deemed to be high-risk in terms of quality and safety. In late 2013, we carried out our first inspections of residential services for people with disabilities under the new regulations and the national standards.[30] The number of inspections in designated centres has increased steadily since 2014 (see Figure 5). The increase was due to the ongoing expansion in the number of designated centres.

Figure 5 – Number of inspections of designated centres — 2014-2023



The general increase of inspection activity was disrupted in 2020, the first year of the COVID-19 pandemic. At the start of the pandemic, inspection activities were suspended for five weeks to consult with public health, secure personal protective equipment and ensure robust measures were put in place to manage the risk of infection posed by inspection activity.

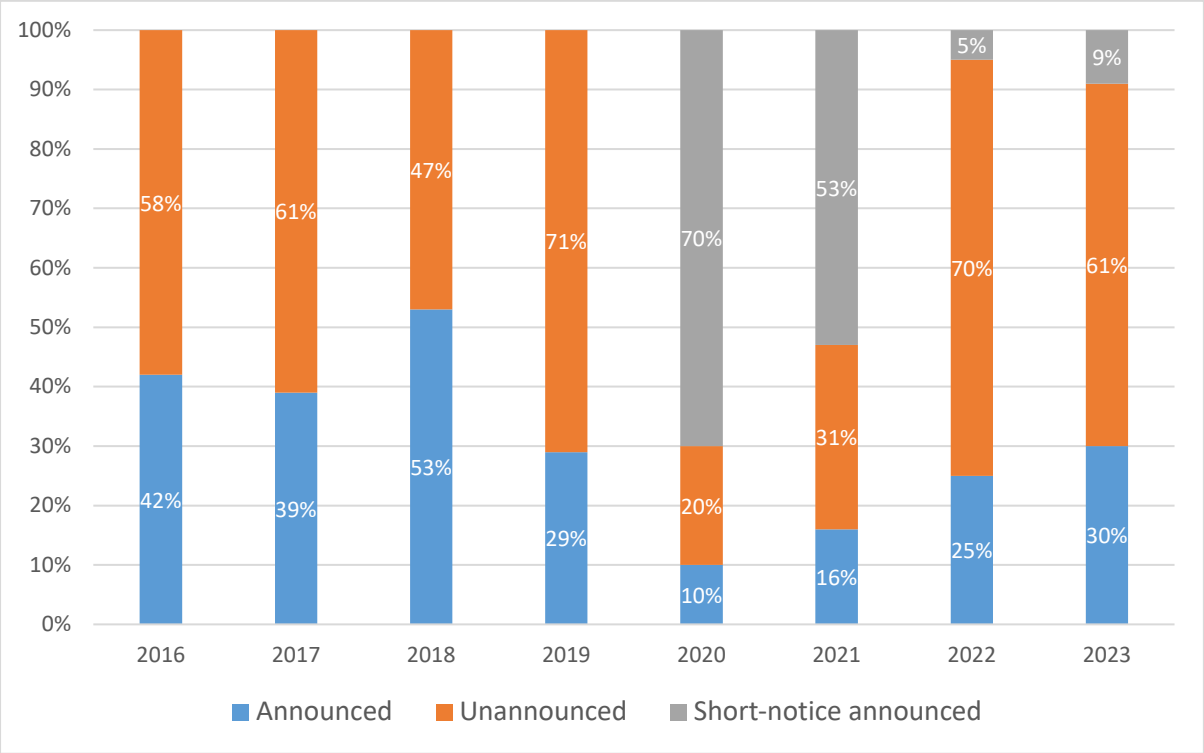
4.6.3 Announced and unannounced inspections

We carry out a mix of announced and unannounced inspections of designated centres. In response to concerns around infection control during the COVID-19 pandemic, we introduced 'short-notice announced' inspections which typically gave a designated centre about 48 hours of notice of an inspection. The short-notice

[30] HIQA-News-Issue-5.pdf.

announced inspection format has been retained and is usually used when an inspector may require a particular person, such as a senior manager or someone representing the registered provider, to be available during the inspection. Figure 6 shows the breakdown of announced, unannounced and short-notice announced inspections since 2016.

Figure 6 – breakdown of announced, unannounced and short-term announced inspections of designated centres — 2016–2023



We continue to carry out as many unannounced inspections as possible. However, announced inspections ensure that residents are aware of when the inspection is due and can arrange to meet with inspectors if they so wish. Announced inspections offer an opportunity for the family and friends of residents to meet with inspectors if they so wish and for residents to complete our survey of what is it like to live in the centre.

We try to announce one inspection for each designated centre in every three-year period. In disability centres, just over 70% of inspections in 2022 were unannounced and 61% were unannounced in 2023.

4.6.4 Changes to assessment of compliance

On commencement of regulation in 2013, our process required that inspectors made judgments of compliance on groups of regulations known as outcomes, of which there were 18 in total. For example, the 'Safeguarding and safety' outcome included the regulation on protection from abuse in addition to the regulation on positive

behavioural support. We changed our approach in 2018 and moved away from the outcome approach towards assessing compliance at the level of individual regulations. This meant that inspectors could choose to inspect any of the regulations, based on their assessment of what was important during the course of an inspection. It also facilitated more accurate data collection which allowed us to better monitor compliance with each regulation.

4.6.5 Thematic or targeted inspection programmes

The Chief Inspector within HIQA has changed the approach to inspections over the past 10 years. At the beginning of regulation in 2013, most of our inspections were focused on areas of high risk and on assessing whether a designated centre was of sufficient quality to be registered. All designated centres successfully attained registration in 2018. Since then, we have continued to adopt a risk-based approach to regulation. That means we will carry out more inspections in centres where we deem there to be the highest risk to residents in terms of quality and safety.

From 2019, we have introduced a new programme of what we term 'thematic inspections'. These inspections aim to promote quality improvement in a specific aspect of care. We encourage registered providers to take a deep look at this specific aspect of care and we provide a range of tools to support them in this quality improvement initiative. Our inspectors will then visit the centre to assess performance in this area.

We have conducted two types of thematic (or targeted) programmes in disability services to date: restrictive practices and infection prevention and control. The restrictive practices thematic programme, based on the national standards, commenced in 2019 and continued into 2023 — albeit with a suspension of these inspections during the COVID-19 pandemic. The infection prevention and control thematic programme, based on the regulations, commenced in 2021 and continued into 2023 (see Table 2).

Table 2 – Number of thematic (or targeted) inspections conducted in designated centres for people with disabilities

Inspection type	2019	2020	2021	2022	2023
Restrictive practices*	54	10	0	0	89
Infection prevention and control**	n/a	n/a	19	411	147

* Restrictive practice inspections were suspended during the COVID-19 pandemic.

** Infection prevention and control inspections only commenced in 2021.

4.7 Number of statutory notifications received

The regulations require registered providers to submit certain information about their designated centres to the Chief Inspector. The Chief Inspector reviews such information and uses it to inform further monitoring activity, including escalation actions and or inspection, and registration renewal decisions. There are two broad categories of notification: three-day (made within 72 hours) and quarterly (made every three months). Incidents such as unexpected deaths and serious injuries of residents must be notified within three days. Quarterly notifications contain information such as minor injuries, restrictive practices or specific issues with the premises that people live in.

The Chief Inspector works with providers to use information to inform and improve the lives of residents where necessary. A centre making multiple notifications of incidents is not necessarily a poorly-performing centre, but one with a good reporting culture and one which is working in the best interests of residents. Things can go wrong in centres, and while we review and risk assess these incidents, we also focus on how the provider has responded to the incident. Therefore, while the notification figures can appear stark, they represent transparent services being provided. It is clear from available data that there is an improved culture of reporting notifiable incidents since the start of regulation.

For three-day notifications, there has been a sustained increase year on year since 2013 (Table 3 on the following page). While notifications of some incidents as a proportion of the total have remained relatively constant (for example, serious injuries and unexplained absences), there has been a significant increase in allegations of abuse. This increase reflects the significant increase in the number of designated centres since the commencement of regulation and a change in reporting culture whereby registered providers are more aware of the types of safeguarding incidents which might be considered for reporting (for example, resident-to-resident aggression). The increase in disease outbreak notifications is due to the COVID-19 pandemic.

Table 3 – Trends in three-day notifications from disability services to the Chief Inspector

***Data based on notifications that were fully closed each year (not on the number of notifications received each year*)**

Type	**2013***	**2014**	**2015**	**2016**	**2017**	**2018**	**2019**	**2020**	**2021**	**2022**	**2023**
Unexpected death	5	71	101	113	99	97	77	98	90	96	73
Disease outbreak	0	49	62	78	58	78	50	3935	5565	3578	357
Serious injury	29	784	1343	1361	1354	1388	1425	1119	1153	1369	1615
Unexplained absence	4	123	193	187	196	192	153	136	146	196	238
Allegation of abuse	30	599	1858	3158	4613	5675	6705	6182	6854	7196	8895
Staff misconduct	3	92	168	211	321	239	321	288	232	259	319
Professional review	0	3	1	0	1	2	0	1	2	2	0
Fire or loss of utilities	33	588	874	984	1496	1509	1538	1316	1346	1474	1808
Total	104	2309	4600	6092	8138	9180	10269	13075	15388	14170	13305

* From the start of regulation in November 2013.

A similar upward trend is observed in quarterly notifications (Table 4).

*Table 4 – Trends in quarterly notifications from disability services to the Chief Inspector**

***Data based on notifications that were fully closed each year (not on the number of notifications received each year*)**

Type	2018	2019	2020	2021	2022	2023
Restrictive practices	1470	4104	4688	5149	5742	6588
Fire alarm activation	359	748	570	678	667	726
Pattern of theft	51	49	29	22	21	18
Minor injury	1083	2916	3152	3419	3797	4218
Expected death	59	110	100	80	101	100
Total	14594	18196	21614	24736	24498	11650

* Quarterly notifications were submitted as one single notification prior to 2018 and have, therefore, been omitted from the figure for the purposes of accurate representation

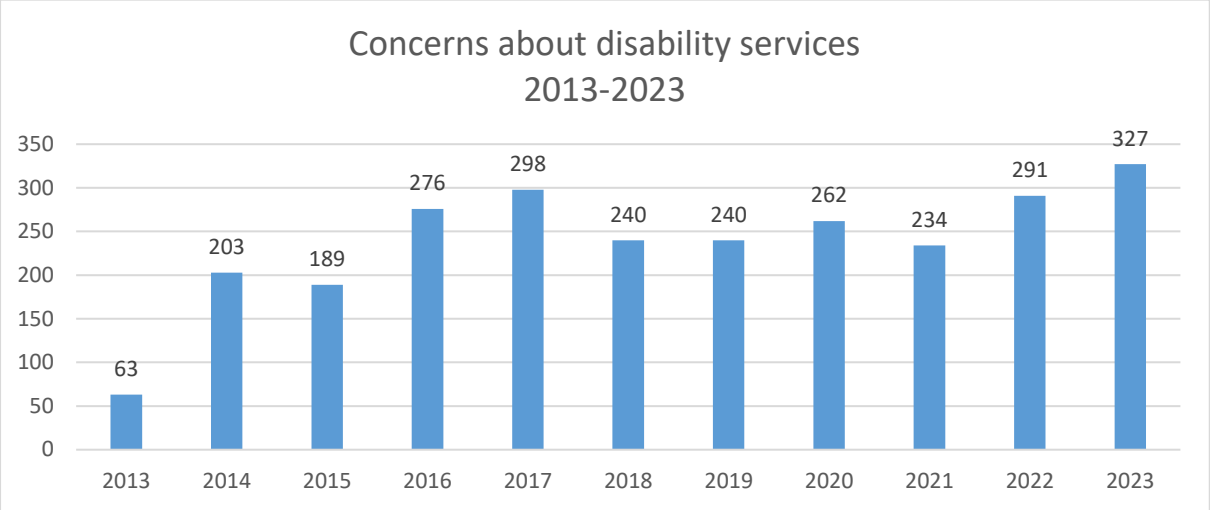
4.8 Concerns received from members of the public and others

If members of the public or any individual has a concern in relation to a designated centre, they can contact our Concerns Team. We term such concerns as 'unsolicited information' and this is received regularly by HIQA from members of the public, including residents of designated centres, their relatives, staff, media and public officials.

Unsolicited information received from the public gives a valuable perspective on designated centres. Along with other forms of information received from registered providers, it is carefully considered with all the other information known about the centre whenever we are making regulatory decisions.

Since commencing regulation, the number of unsolicited information reports received each year has fluctuated up and down (see Figure 7), ranging from 203 in 2014 to 327 in 2023. There were 2,623 concerns related to designated centres for people with disabilities received between 2013 and 2023, an average of 238 per year.

Figure 7 – Concerns received about disability services 2013–2023



4.9 Escalation and enforcement

4.9.1 Introduction to escalation and enforcement

The Chief Inspector has extensive powers under the Act to take action where a designated centre or registered provider engages in a serious or ongoing breach of the regulations. A proportionate approach is taken where we find non-compliance with regulatory requirements. When other means of ensuring sustained compliance have failed, such as a cautionary or warning meeting with providers or a warning letter, further enforcement action may be taken.

4.9.2 What actions can be taken if a residential service is not safe?

If our inspectors find that a designated centre is not safe or the regulations and national standards are not being met, we can use a number of administrative or formal regulatory measures. Some of these are listed in the following section and more detailed information is available in the *Regulation Handbook* on www.hiqa.ie.

4.9.3 Attaching 'restrictive' conditions of registration

A condition of registration sets the parameters within which a designated centre for people with disabilities must operate. Generally, each centre has conditions attached to its registration in relation to the provider's 'statement of purpose' for the centre (the scope of the service), the age range of residents and the number of residents that can live in a centre.

However, on occasion, the Chief Inspector may decide to attach additional conditions to a designated centre's registration. These might include requiring the provider to improve the management of the centre, reduce or limit the number of residents living there or to enhance the premises. These conditions arise from

concerns regarding the governance and management of the centre or the quality and safety of care. Registered providers must meet these conditions in order to continue to be registered[31] and if they do not, the Chief Inspector has additional powers including the cancellation of the registration. Between 2016 and 2023, we attached 434 restrictive conditions to 258 centres, as illustrated in Figures 9 and 10 on the following page.

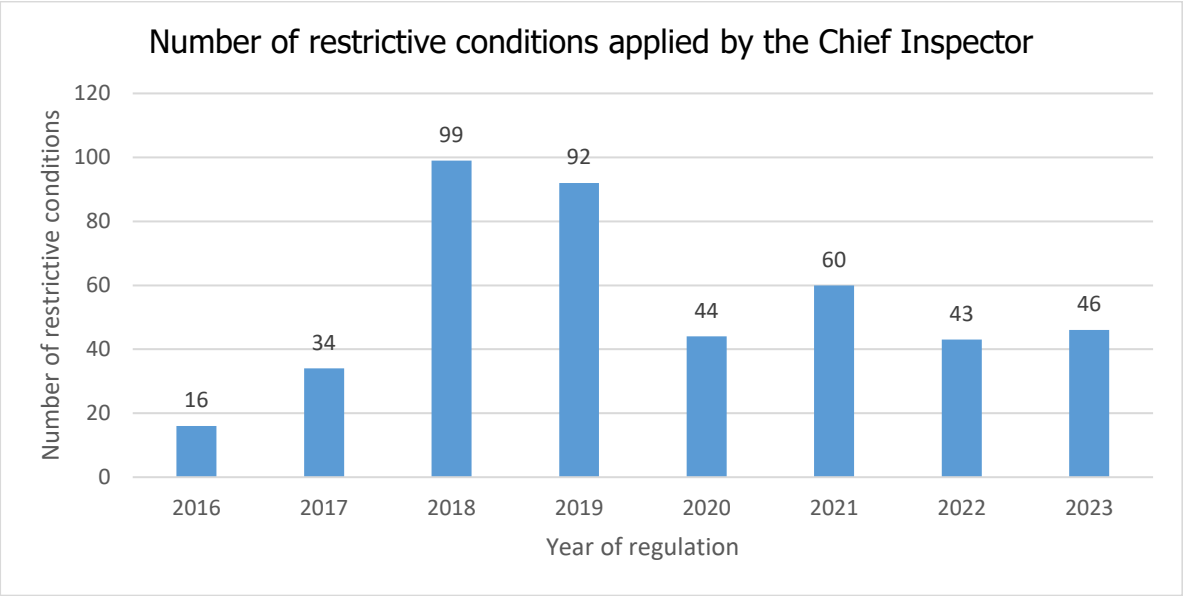
The figures show that 2018 represented a peak in terms of the number of restrictive conditions applied by the Chief Inspector and the number of designated centres involved. The level of overall compliance with governance and management arrangements in inspected centres in 2018 had remained low, with a resulting negative impact on the lives of residents living there. As set out above, the Chief Inspector has a range of legal powers available in order to compel providers to make necessary changes.

At the end of October 2018 (the extended registration cut-off window), additional restrictive conditions had been attached to the registration of 117 centres, which had required the provider to implement targeted improvements within an agreed time frame.[32] Since that year, there has been a steady decline in the number of restrictive conditions in place, and the numbers appear to have stabilised in the past number of years. This indicates that compliance and standards have improved in those designated centres and that this is an effective regulatory tool.

[31] Chief Inspector. Overview Report Monitoring and Regulation of Designated Centres for People with Disabilities in 2021: July 2022. Dublin: HIQA; 2022.

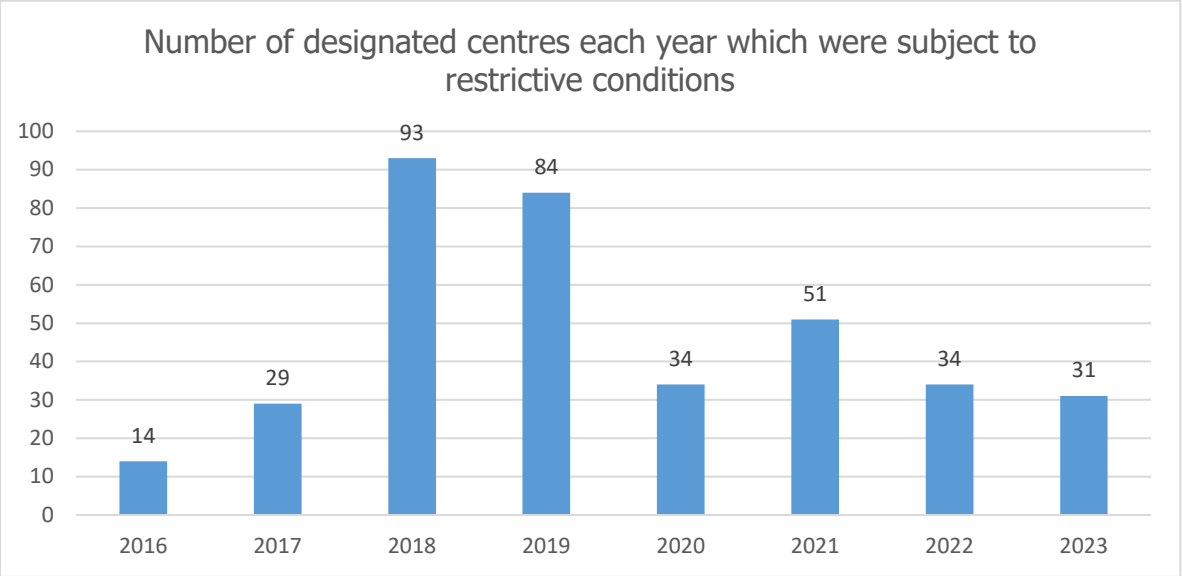
[32] Chief Inspector. Five years of regulation in designated centres for people with a disability: July 2019. Dublin: HIQA; 2019.

*Figure 9 – Restrictive conditions applied by the Chief Inspector, 2016–2023**



* Data before 2016 is unavailable

*Figure 10 – No. of centres each year with restrictive conditions, 2016–2023**



* Data before 2016 is unavailable

4.9.4 Immediate actions and urgent compliance plans

Where registered providers have failed to comply with regulations in a manner which puts the health or welfare of residents at risk, we require them to submit a compliance plan setting out how they will address the issue or issues and how they intend to comply with the regulation(s) in question. In some cases, we direct the registered provider to provide such a plan on the day of the inspection should the risk be deemed significant or within 24 hours of the completion of the inspection. This is referred as an 'immediate action'. In other cases, where we identify

significant failings we will issue the provider with an 'urgent compliance plan' prior to the draft inspection report being issued to the provider for feedback. In such cases, we set the time frame by which the provider must comply. We then monitor that and may go back out to inspect or require the provider to submit an update on its progress against those plans.[33]

Based on trends, we estimate that we issue about 26 of these compliance plans each year (average one every fortnight). This is a matter of some concern to the regulator as these plans are deployed when there are immediate risks to residents which the provider has failed to identify or respond to. To this end, the Chief Inspector welcomes the proposed new powers to be given to the Chief Inspector in the form of compliance notices (in effect, a statutory requirement) to support compliance in residential centres for older people and people with disabilities, complementing the current Section 51 processes under the Act.[34, 35]

Below is an example of a scenario encountered by an inspector which led to the issuing of an urgent compliance plan.

Urgent compliance plan on foot of staffing roster concerns

The inspector reviewed the current roster and observed on the day of inspection three members of staff on duty with, for the most part, one resident in the centre. However, later in the day from 20:00 a single staff member was on the roster to support five residents until 08:00 the next morning. This allocation at night was not in line with the assessed needs of residents as stated by the provider and person in charge.

There appeared to be no plans to address staffing needs to ensure the residents' specific support needs were being adequately and safely met despite this having been identified as a concern in the previous inspection of this centre. As a consequence, the provider was required to respond to an urgent compliance plan.

4.9.5 Addressing issues at the registered provider level

If we identify a trend of similar issues across a number of designated centres operated by the same registered provider, and if the same provider has failed to effectively monitor the quality of services or share learning among its centres, we will see that as an organisational governance issue. While the regulations require us to look at designated centres, where there is significant risk that we may be moving

[33] Chief Inspector speaking at the Oireachtas Joint Committee on Disability Matters, 27 October 2022.

[34] Minister Butler introduces further safeguards for Older People. Dublin: Department of Health; 2024.

[35] Health (Miscellaneous Provisions) (No. 2) Act 2024. Dublin: Government Publications; 2024.

towards cancelling the registration of a number of centres, we engage with registered providers at an organisational level.

Over the 10-year period of regulation, we have invited a small number of providers to meet with us in relation to matters of concern in a number of their centres. In those situations, we require those providers to review their governance arrangements and their effectiveness across all their centres. Here is an example where this approach has been successfully taken for the benefit of residents.

Example of provider-level enforcement leading to positive change

Following a series of poor inspection findings in centres operated by the same provider, a targeted and focused programme of inspections took place. Findings from this inspection programme across all its services nationally demonstrated that the provider was not ensuring support and care to residents, and there were increased risks to the welfare and health of residents. Financial safeguarding concerns relating to both legacy issues and current issues had not been reviewed across all centres by the provider. Inspectors had concerns about safeguarding as well as governance and management, and our findings resulted in the roll-out of a six-month 'national provider targeted governance improvement plan'.

Ultimately, our findings resulted in the closure of one centre, the proposed closure of four centres (which did not have to proceed), warning meetings in relation to two centres, and heightened monitoring activity by the Chief Inspector in one centre. This provider-level engagement took place over six months. Since then, the provider has made substantial system-based changes. Following our extensive regulatory programme, the quality of life of residents has improved and there have been improved governance arrangements at national and local level across the organisation. Higher levels of compliance at designated-centre level have been evident across the country. At the time of writing, the organisation is demonstrating good levels of overall compliance nationally, is reconfiguring services and is now able to consider creating new designated centres.

4.9.6 Cancellation of registration

Cancellation of registration — the effective removal of a provider from operating a designated centre — is one of the strongest measures available to the Chief Inspector. Cancellations are hugely disruptive as they can cause significant upset, uncertainty and anxiety for residents and their loved ones, and there is a requirement for a new registered provider to take responsibility for running the designated centre. The Chief Inspector is acutely aware of the impact that the cancellation of registration can have on the residents, their family, the staff and the provider. As such, we try to work with the registered provider to address the

concerns where possible.[36] Nevertheless, where a serious risk to the health and wellbeing of residents is identified and where a registered provider has not responded appropriately, there have been occasions where there was no option but to take the decision to cancel the registration of a centre.

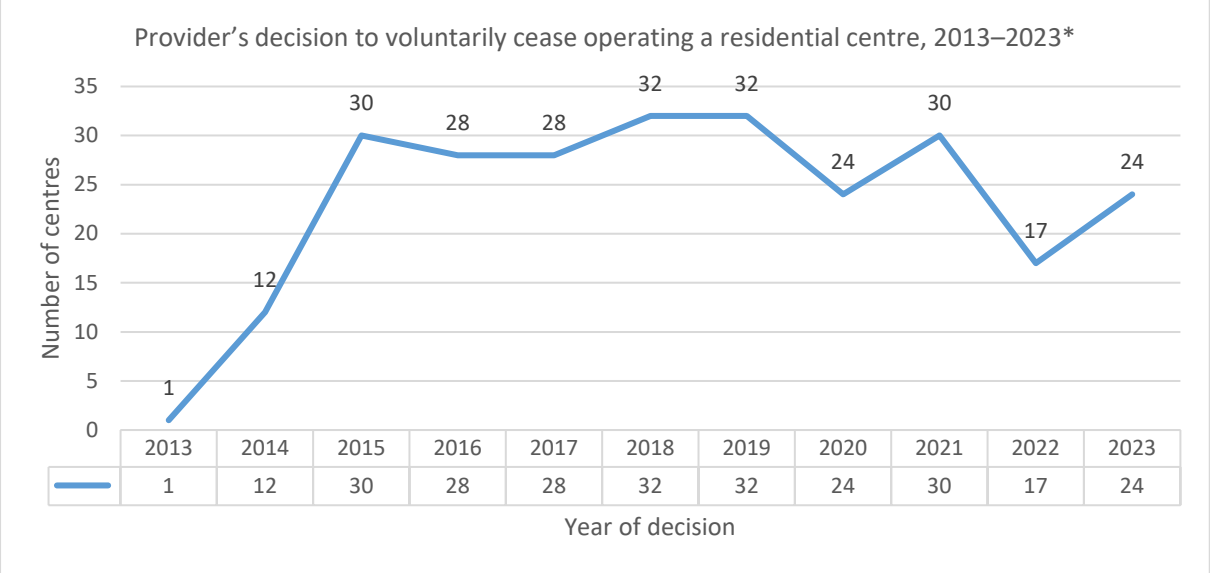
The Chief Inspector cancelled the registration of 15 designated centres between 2013 and 2023. Under the Act, the HSE took responsibility for these centres as the registered provider, with residents continuing to live there even though these cancellations had come into effect. The HSE subsequently made arrangements for other organisations to take over the operation of 11 of these centres and these organisations applied for and were granted registration by the Chief Inspector. Of the remaining four centres, a voluntary organisation now operates one, two closed outright, while another that had been in liquidation was temporarily taken over by the HSE until it closed as a designated centre.

4.9.7 Voluntary decisions to stop operating a centre

There are occasions where registered providers voluntarily decide to stop operating a residential centre. This may be done as the registered provider feels it is unable to carry out the operations of the centre in compliance with regulations, or on foot of correspondence from the Chief Inspector outlining concerns, or other reasons. In most cases, such decisions do not mean that a designated centre closes and its residents have to move elsewhere. Rather, its operations may be carried on by another provider or the provider secures more suitable premises for residents elsewhere. From 2013–2023, voluntary decisions by providers to cease operating particular centres were made in relation to 258 designated centres, affecting an estimated 1,354 residents living in these centres, as illustrated in Figures 11 and 12. These figures exclude data where the Chief Inspector cancelled registration as an enforcement measure.

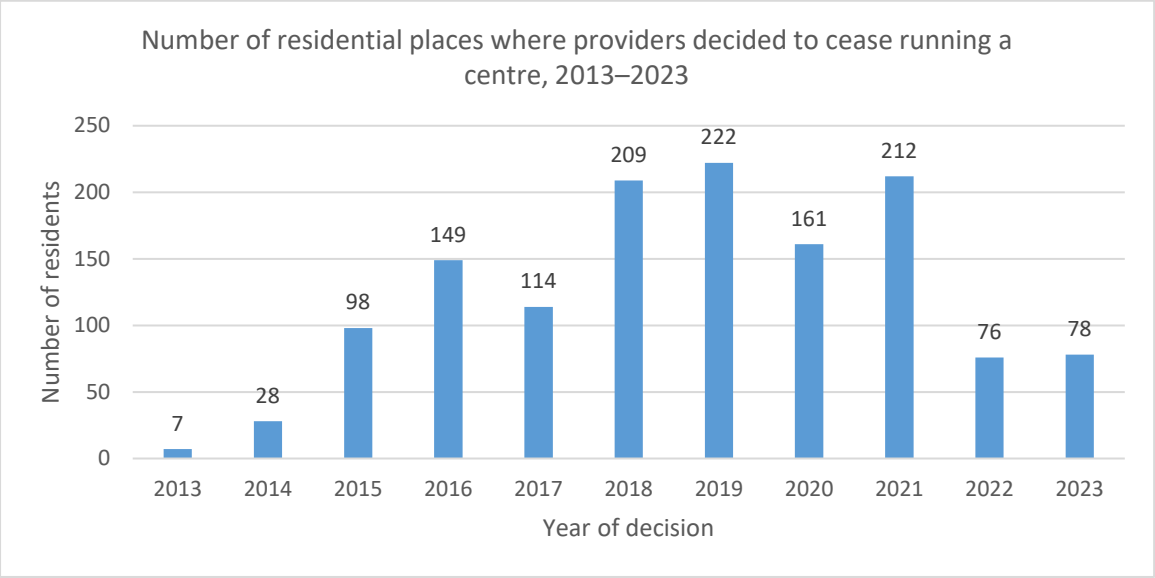
[36] Chief Inspector addressing the Oireachtas Joint Committee on Health, 4 October 2023.

*Figure 11 – Provider's decision to voluntarily cease operating a residential centre, 2013–2023**



* One registered centre temporarily operated by the HSE under the Act closed in 2019 as part of decongregation to the community, having had its previous registration cancelled as part of enforcement action by the Chief Inspector when it had been operated by another provider.

Figure 12 – Number of residential places where providers decided to cease running a centre, 2013–2023



4.10 Emerging trends over the 10 years of regulation — conclusion

The data shows a rise in the number of designated centres and associated inspections and a slow but ongoing process of 'decongregation' — transitioning residents from large, institutional campus-based settings into smaller and better living arrangements in the community. However, almost 25% of people with disabilities living in designated centres were still living in congregated settings at the

time of this report. Our inspections have consistently found that transitioning from congregated settings into designated centres in the community is a necessary step towards improving outcomes and quality of life for residents.

It is also clear from available data that there has been an improved incident-reporting culture since regulation began, indicating that services are more open and transparent about reporting incidents to us. This in turn enables effective learning locally from these events and more positive outcomes for residents. The data from concerns received from the public also echoes the pattern of higher risks seen in centres in the early period of regulation, while in recent years there has been a steady decline in the number of restrictive conditions being applied to the registration of centres, indicating that compliance and standards are improving.

The low level of cancellations of registration of designated centres by the Chief Inspector is indicative of our success in working with poorly performing providers and using the regulatory framework to drive improvements in governance which results in effective improvements in the safety and quality of care and support being provided. This approach is undertaken at organisational level rather than at centre level, and has been used to minimise distress, uncertainty and disruption for residents and their families which can result from cancellation of registration.

Chapter 5: Governance and management

Effective governance and management is a key component of any health and social care service. Our experience of regulating residential disability centres over the past 10 years has provided countless examples of good and poor governance, and the positive and negative impacts on residents as a consequence. Governance and management is a key focus in our inspection process.

The governance and management structures in designated centres play a pivotal role in ensuring a human rights-based approach to care in line with the principles outlined in the national standards. Some of those principles include: providing care and support to promote people's autonomy, promoting the health and development of people, safeguarding and protecting people, promoting integration in the community and delivering responsive and consistent services based on evidence and good practice. Critical to all of this is ensuring that services are planned and resourced effectively by a competent, responsive management and staff team who listen to the voice of the resident.

Ensuring that appropriate governance and management systems are in place promotes key aspects of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), and several articles under this convention. These include:

- Article 12 — Equal recognition before the law
- Article 8 — Awareness-raising
- Article 22 — Respect for privacy
- Article 21 — Freedom of expression and opinion, and access to information
- Article 25 — Health
- Article 28 — Adequate standard of living and social protection
- Article 19 — Living independently and being included in the community
- Article 26 — Habilitation and rehabilitation.

5.1 Quality of governance and management in the early period of regulation

When regulation commenced in 2013, there was a marked difference across a range of registered providers with respect to their level of preparation and readiness for inspections. Some providers went to great lengths to prepare their services for regulation. They familiarised themselves with the regulations, trained staff and engaged with residents about the changes that would need to take place. This positioned them well for the commencement of inspections and ensured that they could respond effectively to findings of non-compliance.

Our inspectors could see that responsible registered providers were willing to change and were engaging positively during inspections. However, there were a number of registered providers that did not prepare as diligently and were, therefore, wholly unprepared for the rigours of regulation.

Furthermore, as the regulator, we quickly formed the view that a small number of registered providers were going to be severely challenged to adequately govern their services in a manner that would provide good outcomes for residents. Some providers had inadequate governance structures at senior level, poor lines of accountability and an unwillingness to improve or learn from inspection findings. This translated into poor responses to findings of non-compliance and meant that residents were being placed at risk. Below is an example of one provider whose governance arrangements were deemed unfit and which was then subject to enforcement proceedings by the Chief Inspector that resulted in it being replaced as registered provider for each of its three designated centres.

Poor findings on governance and management — 2016 inspection

This was the centre's sixth inspection and was unannounced. The purpose of the inspection was to inspect against failings identified on the most recent inspections completed [in] May and October 2015. Following these inspections [and] due to the serious concerns which were found on inspection, the chief executive officer (provider) and the chairman were asked to attend a meeting at HIQA's Dublin office. Subsequent to this meeting the provider made assurances the centre would make significant improvements within a period of eight weeks. This inspection took place 12 weeks later to optimise the opportunity for the provider to implement improvement.

At the time of the inspection, eight residents resided at the centre. The statement of purpose for the centre describes the centre as providing autism specific services for adults with a primary diagnosis of autistic spectrum disorder. Residents had complex and varied support requirements. During the inspection, the inspectors communicated with a number of the residents, reviewed documentation, made observations and spoke with staff.

Overall, there continued to be significant and sustained non-compliances with the Health Act 2007 as amended. The inspectors found that although the provider had committed to completing the actions from the previous inspection(s) to make significant improvements, this was not evident at the time of inspection. The general manager of services and the person in charge told the inspectors they were unaware of these commitments provided to HIQA by the provider. As with previous inspections, major non-compliances were found; 14 outcomes were inspected against, eight of which were found to be major non-compliances.

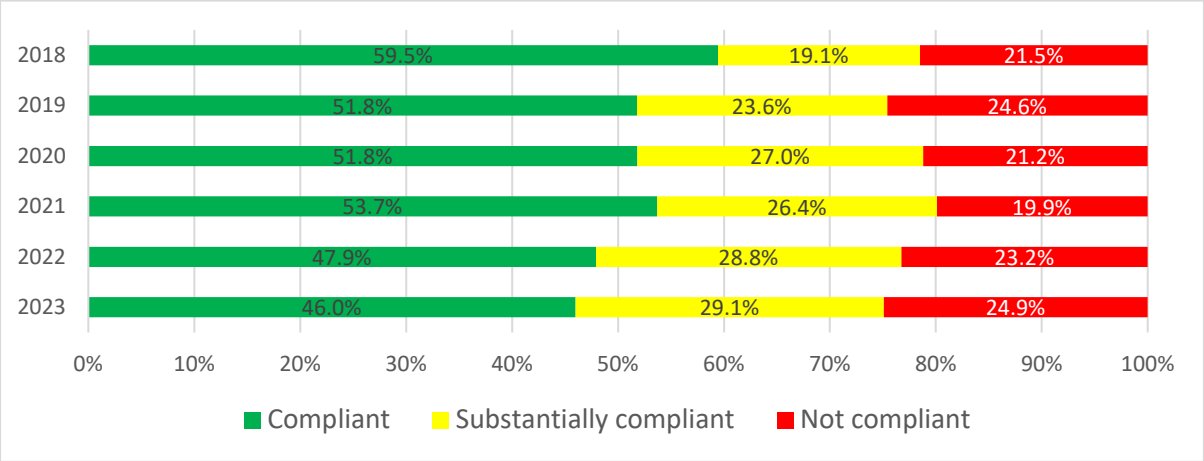
Overall, inspectors were not satisfied that the provider had put system in place to ensure that the regulations were being met. This resulted in poor experiences for residents…. The inspectors found that the lack of effective governance and management systems had resulted in:

- inappropriate guidance for the use of chemical restraint
- behaviour support plans not in place or not effectively guiding practice
- inadequate safeguarding measures to ensure residents were protected and felt safe living in the centre
- risks to residents were not being appropriately managed or responded to
- a lack of continuity of care
- unclear management and reporting structures
- staff not trained to meet the assessed needs of some residents.

5.2 Governance and management during COVID-19

In line with public health restrictions and in order to protect the health of residents, most providers were required to remotely monitor the operations of their centres. As a consequence, our inspectors observed a marked deterioration in the quality of governance and oversight over the course of the pandemic and we attribute this to the inability of management to be present in centres during this time (see Figure 13 below for trends in compliance with the governance and management regulation). While remote monitoring was mostly unavoidable, this example serves to demonstrate the importance of having a management presence in centres.

*Figure 13 – Compliance levels with regulation on governance and management**



* Data prior is 2018 is unavailable due to changes in how we assessed compliance.

As the public health measures around the pandemic subsided and working and social life began to return to normal, our inspectors noted that some providers struggled to

re-establish effective oversight of their services. It became apparent that a reliance on self-reporting by local managers — absent of any validation at organisational level — was an ineffective means of ensuring quality. Ultimately, this meant that some providers failed to identify issues in their services. This led to a general, albeit slight, decrease in non-compliance across all regulations in 2022. This example serves to underline the importance of effective governance and having a regular management presence in services.

5.3 Our continued focus on governance and management

Our inspectors carry out inspections to determine the level of compliance with regulations. Ultimately, this is a process to determine how effective a registered provider is in terms of running and properly overseeing its designated residential centres. It is acknowledged that even the most well-run services can experience difficulties, emergencies or unforeseen events. Often, it is at times like the pandemic that effective governance and management shines most brightly. Registered providers that have good governance systems in place are capable of responding to crises, they have good lines of communication and they are responsive and can take action swiftly.

Our inspectors almost always assess the regulation on governance and management while on inspection. They speak with residents to see if they are familiar with the management of a service, they ask staff about reporting structures and ongoing supervision arrangements. They speak with the person in charge and other senior managers to determine how well they know the residents of the service and their needs. It is often the case that well-run services are the ones that can identify their own shortcomings and discuss these openly with inspectors. This indicates that they are focused on quality improvement and are vigilant in monitoring key aspects of their service.

It is a requirement of the Health Act 2007 that the Chief Inspector be assured that a registered provider is a 'fit person' to manage a designated centre. As such, each of the key people involved in the management of designated centres are assessed for fitness by our inspectors as part of the regulatory process. Fitness for the purpose of registration and ongoing regulation is, among other things, our confidence in the ability of the registered provider, person in charge and other managers to:

- perform his or her or its statutory role
- deliver a service that:

  — provides safe, suitable and sufficient care

  — protects the rights and promotes the wellbeing and welfare of residents

- comprehensively understand and comply with regulations and national standards
- have appropriate governance arrangements in place to assure themselves of the quality and safety of the services they are registered to provide.[37]

This assessment is a standardised and consistent approach that seeks to determine:

- if a person is of good character
- is competent to perform their role
- is honest and transparent in their dealings with the regulator, and
- does not have a judgment against them that would impact on their ability to carry on the management of a designated centre.[38]

Inspectors will usually interview key management and review documentation in order to determine a person's fitness.

Throughout the past decade we have worked with registered providers to drive improvements in governance and deliver higher quality services for residents. Transformations of governance and management can be difficult processes. It can often mean a change in culture as well as a change in management and oversight practices. However, these transformations are achievable. The following example illustrates how one registered provider made significant changes to it governance and management that resulted in improvements for residents.

Improvements in governance and management — case study from 2022

Over a series of inspections of a range of the provider's designated centres, inspectors found that residents' right to a safe place to live and good quality of life were not being upheld. Inspectors found high levels of institutionalised practices that were focused on managing large groups of residents rather than supporting each person to live their best life or ensuring that the service provided was underpinned by a human rights-based approach. These practices included residents' daily routine being determined by staff rosters rather than the wishes of residents, residents living in overcrowded situations, a failure to respond to the healthcare and social care needs of residents and a failure to support residents to participate in their local community. In addition, safeguarding issues and ones

[37] Regulation Handbook.

[38] Guidance on the assessment of fitness for designated centres. Effective January 2018. V2.1: Revised November 2023.

that impeded on residents' rights were not identified as such and, therefore, residents were not at all times experiencing the right to make choices, the right to be heard or live a life of their choosing.

The Chief Inspector required that the provider review its governance from the Board of Directors through to local management and to undertake actions to significantly improve the effectiveness of its governance arrangements and improve the safety and quality of life for residents. Inspectors undertook a series of inspections during this time to verify that the provider was implementing its action plan and that the actions were driving an improved quality of life for people with disabilities living in their designated centres.

While it took some time for these changes to make an impact, that impact has been very effective and inspectors are now finding high levels of compliance in the majority of the provider's centres. These levels of compliance are reflected in the good quality of life for people with disabilities living in those centres. Staff are now proud to show how they and the organisation prioritise and uphold the rights of residents. The provider has also incrementally provided more suitable arrangements for residents to live, and has supported residents to make choices about who they wished to live with. It has also supported a number of residents to move from a congregated setting into their local community, which inspectors have found has had a significantly positive impact on their quality of life.

In each of our annual overview reports, we have noted the positive impact for people with disabilities in organisations where providers have established a strong human rights-based culture which is supported by robust governance oversight arrangements by the executive management teams and by the boards of directors.

During 2022, we re-established our provider roadshows following curtailment of these due to COVID-19 and held four of these events across the country. The theme was *The Impact of Good Governance: The Right(s) Approach*. Those roadshows were attended by over 520 managers and provider representatives. We followed up with a series of webinars along the same theme in 2023 which had an attendance of 2,760 participants. Then in 2024, the Chief Inspector hosted a seminar for the chief executive officers and board members of provider organisations, which again focused on the impact of good governance and which was launched by the Minister of State with responsibility for Disability, Anne Rabbitte TD.

Good governance underpins good performance in other key areas of care and support for people with disabilities in designated centres. The following chapters discuss our findings in relation to a number of those key areas.

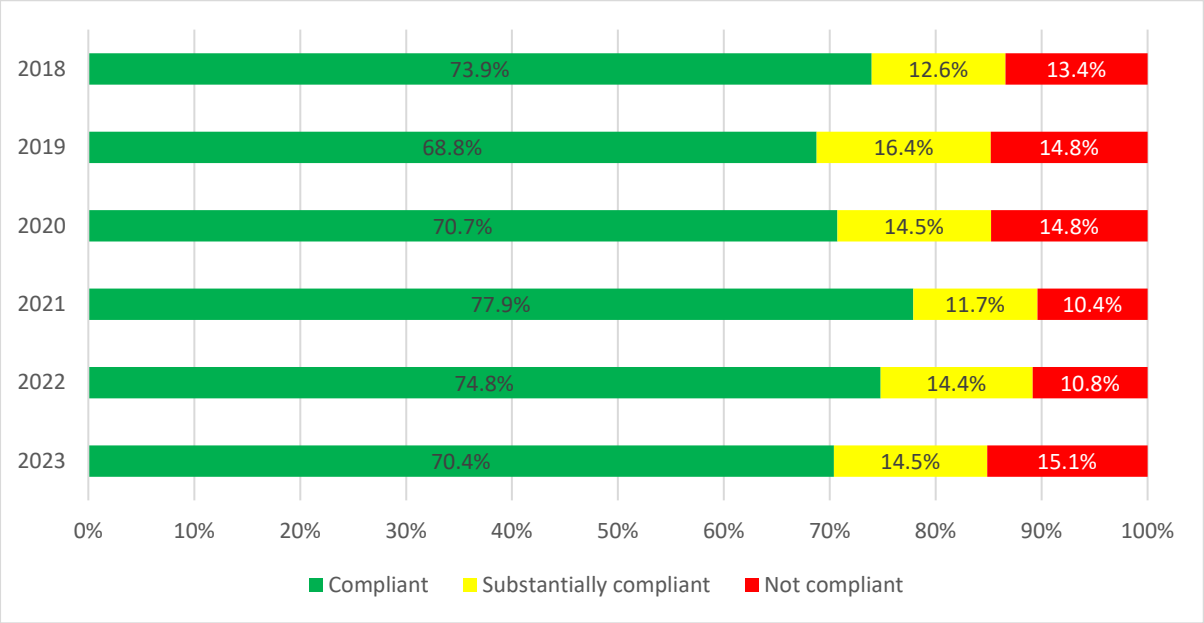
Chapter 6: Human rights-based approach to care

This chapter focuses on the theme of human rights. Providers have embarked on a journey of raising awareness of a human rights-based approach to care, but recent inspections show that there is still some way to go to fully embrace this concept. The issue came to fore during COVID-19 when residents were subject to stringent restrictions on their choices, movement and liberty — similar to the rest of the population.

Looking back, it is a matter of historical record that various institutions during the opening century of the Irish State had a sometimes poor track record in terms of providing care. Times have changed significantly in the past two decades, and the introduction of regulation of residential services for people with a disability was a seminal moment on that journey of change. When the Chief Inspector in HIQA commenced regulating, we saw many examples of poor care that negatively impacted on residents' human rights. As time progressed, many providers, where required, started to turn things around. Nonetheless, this chapter shows some examples of how this is often still in its infancy.

The inspection findings from 2018 onwards found a good level of compliance in relation to residents' rights. However, there continues to be a persistent level of non-compliance which means that the rights of residents being accommodated in those residential centres are not being promoted and protected.

*Figure 14 – Compliance levels with regulation on residents' rights**



* Data prior is 2018 is unavailable due to changes in how we assessed compliance.

6.1 Introduction to human rights-based approach to care

As a nation, historically Ireland has a poor track record in terms of caring for people that need care and support. These people may have had disabilities, mental health problems, illnesses or simply been outcasts from society, such as young, unmarried women who had babies, the homeless or children committed to industrial schools.[39] It is a matter of historical record that many people suffered due to neglect and poor treatment in institutions across the country. In essence, their basic human rights were not upheld and they were seen as somehow inferior. Conditions in some local authority county homes (the successor to the pre-independence workhouses) for mostly older people and people with disabilities were generally very poor following the foundation of the State up until at least the 1950s and 1960s, and discriminatory towards unmarried mothers who also lived there.[40] It is easy to think that these institutions are from a by-gone era but the fact is that many of them operated until as late as the 1990s in Ireland — albeit in the case of mother and baby homes with a transition from institutional care to support with independent living[41] — and some of them became congregated settings for people with disabilities which continue to operate today. While the introduction of regulation in 2013 was very welcome, ongoing regulatory reform is necessary to ensure that services provided have the capacity and capability to deliver care and support that meet people's needs in a manner that offers quality, safety and the protection of people's rights.[42]

6.2 Using regulation to support human rights

Regulation is one means by which to address poor standards of care and support and promote a human rights-based approach to the provision of care and support. Prior to the commencement of regulation of residential services for people with disabilities in 2013, HIQA was aware that there were some residential disability services that were providing poor care and were infringing people's basic human rights. Our focus during the early days of regulation was to identify the designated centres presenting the highest risk to residents and taking action to improve their quality of life. Some practices were clearly breaches of a person's human rights. For example, restraining a person in a chair or locking them in a room means their liberty is impacted. Unfortunately, and as outlined earlier in this report, the Chief Inspector did find many situations where these practices were still being used during the early days of regulation, and indeed to this day our inspectors find instances of

[39] The Cambridge Social History of Modern Ireland (2017).

[40] Executive Summary of Mother and Baby Homes Commission of Investigation Final Report: 30 October 2020.

[41] Ibid

[42] Former HIQA CEO Phelim Quinn addressing the Oireachtas Joint Committee on Health, 23 March 2021.

this occurring, particularly when there are staffing shortages. Presented here are some examples of poor care that impacted on the human rights of residents, seen within the first four years of regulation.

Infringements on the human rights of residents — 2015 inspection

Inspectors found that residents' rights and dignity were not fully respected or promoted in the designated centre. On arrival into the centre, inspectors observed a resident being supported with personal care in his bedroom. The doors to this resident's room were open, and other residents and visitors had [a] clear view of this from the communal sitting room. This was not ensuring residents' dignity during intimate care.

Inspectors found that residents were not always spoken of in a respectful manner by staff. For example, behaviours of concern were described as "disruptive" and "demanding"… Inspectors also determined that information and communication regarding residents was not always done in a discreet or respectful manner. For example, on residents' arrival into the centre following their day programme, inspectors heard staff describe residents who were "wet" and needed changing to other staff.

Inspectors observed that residents' personal folders and daily record books were stored in the communal living room in a broken press. The door had fallen off the press and personal information was not securely stored. Inspectors found that the centre was not treated as a home for residents, but as an open building. Inspectors noted 13 different access points into the centre, and observed numerous visitors coming in and out of the centre throughout the course of the day without knocking....residents from other designated centres had freely come into the centre and were walking around unsupervised. This was not promoting the centre as a homely environment, or ensuring the dignity and privacy of residents within their home.

Infringements on the human rights of residents — 2015 inspection

At the previous inspection, inspectors observed the inappropriate restraint of residents, including prolonged periods of restraint in chairs for most of the day. In response to that finding, the provider stated that arrangements would be made for the release of residents from restraint for at least 10 minutes in every hour. Inspectors found that the provider was not implementing its own actions, but also found that the actions of the provider compromised the wellbeing of the resident[s]. The provider had not undertaken proper assessments to ensure the use of restraint was a last measure and that it was the least restrictive for the

shortest duration possible. This approach to restraint was a significant breach of the rights of residents.

Infringements on the human rights of residents — 2017 inspection

As on the previous inspection, it was again found that the designated centre did not meet the assessed needs of all residents, as there was an unsuitable mix of residents in the centre. In particular, the centre was failing to meet adequately one individual resident's emotional, social or developmental needs. As was found on the previous inspection, as a result of the unsuitable mix of residents in the centre, it was not demonstrated that residents were being adequately protected from injury and harm by their peers.

Other breaches of human rights can be more subtle and deeply embedded in the culture of a service. For example, people may have 'freedom from' certain things such as abuse or neglect. But they often do not have the 'freedom to' do what they want, whether that be engaging in an activity, being part of the local community or expressing themselves. As the regulator, the Chief Inspector identified this as a key shift necessary in the culture of a range of designated centres and registered providers in order to genuinely provide care and support that helps people realise their full potential and promotes their human rights. The following example describes where staff failed to recognise institutionalised practices as potentially being a breach of people's rights.

Institutional practices in the centre meant that residents could not avail of activities outside the designated centre when staff lunch breaks were being facilitated between the hours of 12 and 4pm most days.

6.3 Shift of focus from high-risk regulation to a human rights-based approach

The early years of regulation of designated centres for people with disabilities involved an intensive focus on the areas of highest risk and the poorest quality services. Regulation was a learning process for the Chief Inspector, providers, staff and management in designated centres. During those initial years of regulation, our inspectors were finding significant issues primarily relating to safeguarding, protection and risk.

As time progressed and quality and regulatory compliance gradually improved, many providers were then in a position to shift the focus towards providing a human rights-based approach to care. For example, in one service, we saw a significant shift in the staff culture and awareness of people's rights which directly benefitted

residents. In previous inspections, a poor culture had been observed, and residents were not being placed at the heart of the service. An inspection report of this service later reported on this turnaround:

As regulatory compliance improves, a human rights-based approach emerges

A resident who liked to go out for lunch every Friday in one of the local hotels informed their key worker that they would like to work in a hotel. The key worker, in consultation with the resident, put a plan of action in place so as the resident could realise their goal. They consulted with a local hotel and enquired if the resident could avail of some work experience each week. The hotel was agreeable to this and at the time of this inspection, the resident had secured a weekly work placement with the hotel. Staff reported that this was a great achievement for the resident as their self-esteem, independence and confidence had flourished and, they were very much enjoying their job.

Overall, through a focus on risk and safety, HIQA believes that the first five years of regulation helped to address the very significant and persistent human rights issues in designated centres for people with disabilities. Providers that had been a concern to the Chief Inspector previously are now providing some of the best performing services following regulatory input. However, compliance data shows other provider organisations have deteriorated. Nonetheless, regulation gives the State a systematic means to identify such deterioration and a framework for challenging providers to address issues as they emerge. As the regulator, the Chief Inspector must continue to adapt to changing circumstances and changing compliance. So while non-compliance rates for residents' rights is down in 2023 compared to 2018, we are more focused on assessing this critical regulation than ever before.

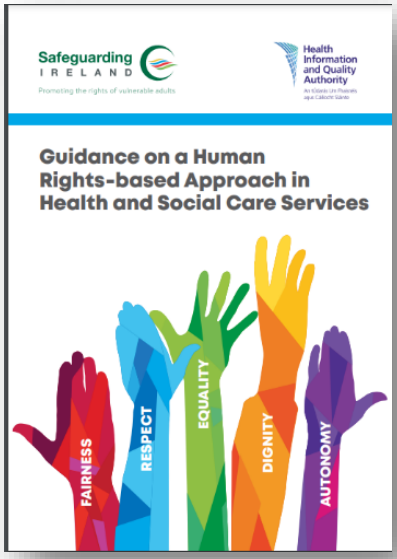
6.3.1 Human rights and the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)

A key milestone in the journey towards delivering a human rights-based approach to care was Ireland's ratification of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in 2018. The Convention applies established human rights principles from the UN Declaration on Human Rights to persons with disabilities. This ratification underpinned the State's commitment to ensuring that people with disabilities could be empowered to live independent and fulfilling lives.

Our focus on a human rights-based approach aligns with United Nations Convention on the Rights of Persons with Disabilities. Several articles of the convention are relevant in the context of a human rights-based approach:

- Article 14 — Liberty and security of person
- Article 16 — Freedom from exploitation, violence and abuse
- Article 17 — Protecting the integrity of the person
- Article 23 — Respect for home and the family.

6.3.2 Guidance on a human rights-based approach



In an effort to build on this momentum, HIQA in conjunction with Safeguarding Ireland produced a guidance booklet in 2019 entitled *Guidance on a Human Rights-based Approach in Health and Social Care Services.*[43] This guidance is structured around the FREDA human rights principles, which are:

- Fairness
- Respect
- Equality
- Dignity
- Autonomy.

The guidance also identifies which conventions (for example, the European Convention on Human Rights and the United Nations Convention on the Rights of Persons with Disabilities) apply with respect to each of the five FREDA principles. Registered providers are encouraged to use this guidance to support staff to provide high-quality care in their services and to embed human rights-based principles into their everyday practices.

6.3.3 Human rights training for all inspectors

In 2022, all inspectors of social services received human rights training. As a result, our inspectors are more confident about speaking about rights with providers, staff and residents, and later reporting on them in our inspection reports. We have also observed that while it is not a mandatory requirement, staff in a number of designated centres are receiving training in how to provide care and support with a human rights-based focus. The process may be slow and there is more we can do to

[43] Guidance on a Human Rights-based Approach in Health and Social Care Services (2019).

keep the focus on rights, but change is happening and registered providers do not want to be seen to be breaching the rights of individuals.[44]

HIQA has also developed an e-learning programme on a human rights-based approach that staff in centres can access. By the autumn of 2023, almost 35,000 people had completed this programme.[45] We have also looked at how we speak to residents about their rights, how we report on that and how we ensure that our inspectors have the confidence to call out those rights when they see them not being promoted or respected.[46]

Presented below is an example of how regulation and the initiatives outlined above have promoted a human rights-based approach to care in a designated centre.

Promoting a human rights-based approach to care — 2023 inspection

Staff spoke about how human rights training encouraged them to think about risk for residents differently. They gave the example of a resident who wanted to get a tattoo. The staff and resident explained to the inspector how they had discussed their choices, the risk of pain to expect, and the aftercare required, which supported the resident to make an informed decision. The resident showed the inspector their new tattoo and explained how they were supported to keep it clean while it healed.

Promoting a human rights-based approach to care — 2022 inspection

The registered provider of a designated centre in the northwest of the country that was inspected in 2022 had incorporated the FREDA principles into its weekly residents' meeting with good effect. This had followed staff training on delivering a human rights-based approach to care. At the time of the inspection, nine residents were living there and residents were very well informed of their rights. Their autonomy was respected and promoted and this meant that residents were actively involved in the running of the centre, and they took a lead role in making decisions about their own lives.

Resident's rights were promoted and protected in this centre. Weekly resident meetings were held in each house. Minutes from these meetings showed that staff in the centre supported the residents to make choices about the running of

[44] Chief Inspector speaking at the Oireachtas Joint Committee on Disability Matters, 8 November 2023.

[45] HIQA CEO Angela Fitzgerald speaking at the Oireachtas Joint Committee on Health, 4 October 2023.

[46] Chief Inspector speaking at the Oireachtas Joint Committee on Disability Matters, 27 October 2022.

the designated centre. The meetings were also used as opportunities to inform residents of the principles of fairness, equality, dignity, respect and autonomy and how these underpinned their care. Overall, residents in this centre had a good quality of life that was underpinned by a human rights-based approach to care and support. Staff were knowledgeable on the needs of residents and the supports that they required. They respected the residents' rights and choices.

Promoting a human rights-based approach to care — 2022 inspection

The registered provider had ensured that the centre was being operated in a manner that respected the rights of residents. Although one of the homes was located on a congregated campus, the provider and person in charge were promoting a human rights-based approach to residents' care and support. Residents were involved in decisions about their care and support, and could exercise choices in their daily lives; for example, their meals, daily routine, and activities. Residents attended house meetings which provided a forum for residents to make choices, share information, and participate in the running of the centre.

Human rights were discussed at meetings, and a different right or principle was discussed at each meeting to support residents' awareness and understanding. There was also easy-to-read information for residents on national standards, advocacy, capacity, and complaints. The person in charge had made a referral to the national advocacy service and the speech and language department to support one resident to make a decision about their healthcare. The registered provider had ensured that each resident's privacy and dignity was respected and upheld. Each resident had their own bedroom, and there was adequate communal living space. Residents' personal information was securely stored to protect their privacy.

However, further improvements are needed across a number of services to truly transition to and embed a human-rights based approach to care and support, as can be seen in the following relatively recent reports. These examples show that awareness of residents' needs are required to ensure that residents' rights are always to the fore. In the first example, the regulation on residents' rights was non-compliant, while the regulation on individual assessment and personal planning was substantially compliant. In the second example, the regulation on residents' rights was non-compliant.

Shortfalls in a human rights-based approach to care — 2022 inspection

For residents who had been recently admitted into the designated centre, there was an absence of a human-rights based approach to decisions and supports. For example, the provider had not ensured residents had access to an independent advocate to support them in their decision-making, and the views of residents and impact of the move on their wellbeing had not been fully considered… for example, where residents demonstrated signs of distress or unhappiness on trialling visits to the centre, or had changing presentations in their needs or mood following admission. While some transition plans had been created to support residents with their move, they did not give sufficient information to support residents moving from one location to another. Staff working in the designated centre did not have concise information available to them to assist new residents to move into the centre in a way that would fully support them to make the adjustment positively.

Shortfalls in a human rights-based approach to care — 2022 inspection

Residents' rights to have freedom of movement and to exercise choice and control in their daily lives were negatively impacted in the centre due to compatibility of residents in one house, staffing resources and inaccessible transport. Meals continued to come from a centralised kitchen and at the time of the inspection, residents or staff were not cooking meals in their own home. In one of the houses, due to safeguarding concerns, one resident was required to go into their bedroom while another resident had their personal care needs attended to. This was due to a lack of availability of staff supervision to ensure that the resident was not subjected to any incidents by another peer. Access to transport was another issue which had a negative impact on residents' lived experiences in the centre. Many of the staff working in the centre did not drive the transport, which limited the residents' opportunities to access community settings. Another resident was unable to use the centre's transport as it was not accessible for them. This was identified by the provider and alternative solutions were being explored.

6.4.4 Raising human rights at parliamentary level

We have promoted the concept of human rights-based care and support at parliamentary committees. For instance, in November 2023, our Chief Inspector and Deputy Chief Inspector attended the Oireachtas Joint Committee on Disability Matters to discuss rights-based care for people with disabilities. In her opening statement to that meeting,[47] the Chief Inspector emphasised the importance of meeting with and hearing from residents and people using services, and how we continue to enhance our human rights-based approach to regulation. On 24 January 2024, the Oireachtas Joint Committee on Disability Matters published its report *Towards harmonisation of national legislation with the United Nations Convention on the Rights of Persons with Disabilities*. There were a number of references to our work in disability services throughout the report.[48]

[47] Opening Statement by the Chief Inspector to the Oireachtas Joint Committee on Disability Matters, 8 November 2023.

[48] Joint Committee on Disability Matters. Towards harmonisation of national legislation with the United Nations Convention on the Rights of Persons with Disabilities: January 2024.

Chapter 7: Restrictive practices

7.1 Introduction to regulation of restrictive practices

This chapter focuses on the theme of restrictive practices in designated centres and how as the regulator we challenged poor practices seen in the early days of regulation and then later went on to work with providers to help change attitudes and cultures. Our work in this area is informed by assessing key regulations that affect people's rights and supports and by the United Nations Convention on the Rights of Persons with Disabilities.

7.2 United Nations Convention on the Rights of Persons with Disabilities and restrictive practices

Our focus on restrictive practices contributes to improvements in the lived experiences of residents. The regulations set out what is required if a provider uses any form of restrictive practice. Their use should also be informed by the United Nations Convention on the Rights of Persons with Disabilities. Several articles of the convention are relevant in the context of restrictive practices:

- Article 14 — Liberty and security of person
- Article 15 — Freedom from torture or cruel, inhuman or degrading treatment or punishment
- Article 16 — Freedom from exploitation, violence and abuse
- Article 17 — Protecting the integrity of the person
- Article 23 — Respect for home and the family
- Article 31 — Statistics and data collection.

Reducing and eliminating restrictive practices contributes to increased liberty for people living in designated centres. It also serves to reduce the likelihood of abuse as some restrictive practices, when implemented inappropriately, can be a form of abuse.

7.3 What are restrictive practices?

Restrictive practices — also referred to as a 'restrictive procedure' — are defined in the regulations as the 'intentional restriction of a person's voluntary movement or behaviour'.[49] While somewhat difficult to define in practice, they can be broadly described as the intentional restriction of a person's movement or behaviour in some way.

[49] S.I. No. 367/2013 - Health Act 2007 (Care and Support of Residents in Designated Centres for Persons (Children and Adults) with Disabilities) Regulations 2013.

Restrictive practices are sometimes used in circumstances where a person represents a danger to themselves or others (for example, a physical hold to guard against aggressive behaviour). They are also used to restrict access to a person's environment in cases where there may be hazards or risks (for example, a locked door or room). Restrictive practices, by their nature, impact on the resident's right to freedom. Because of this, the regulations place strict controls on their use in designated centres, and also require detailed record-keeping and notification to the Chief Inspector in relation to their use. Broadly speaking, to protect residents' rights, they are to be avoided if at all possible. In cases where they are deemed necessary, providers must ensure that there is a high bar in the quality of evidence to support their use, their use is proportionate to the risk, for as short a duration as possible, are kept under regular review and that they are a last resort.

There is no question that the use of restrictive practices was a common feature in many health and social care settings in Ireland in the past. Indeed, our inspectors found many examples of poor and outdated practice in the early days of regulation, as seen in this inspection report from the initial years of regulation:

Restrictive practices impacting on the rights of residents (2015)

Inspectors found that the rights of residents were not adequately respected due to the inappropriate use of restraint. For example, restraint measures were being used for excessively long periods of time due to inadequate staff numbers and the poor physical environment. In addition, there were inadequate records of when the restraint measures were being used. Staff informed inspectors that any release from the restraint during the day were dependent upon staff availability and was not planned on the basis of residents' needs.

However, there was also good practice seen in services in 2015, including in the following centre where the then overarching outcomes on (a) safeguarding and safety, and on (b) residents' rights, dignity and consultation were fully compliant:

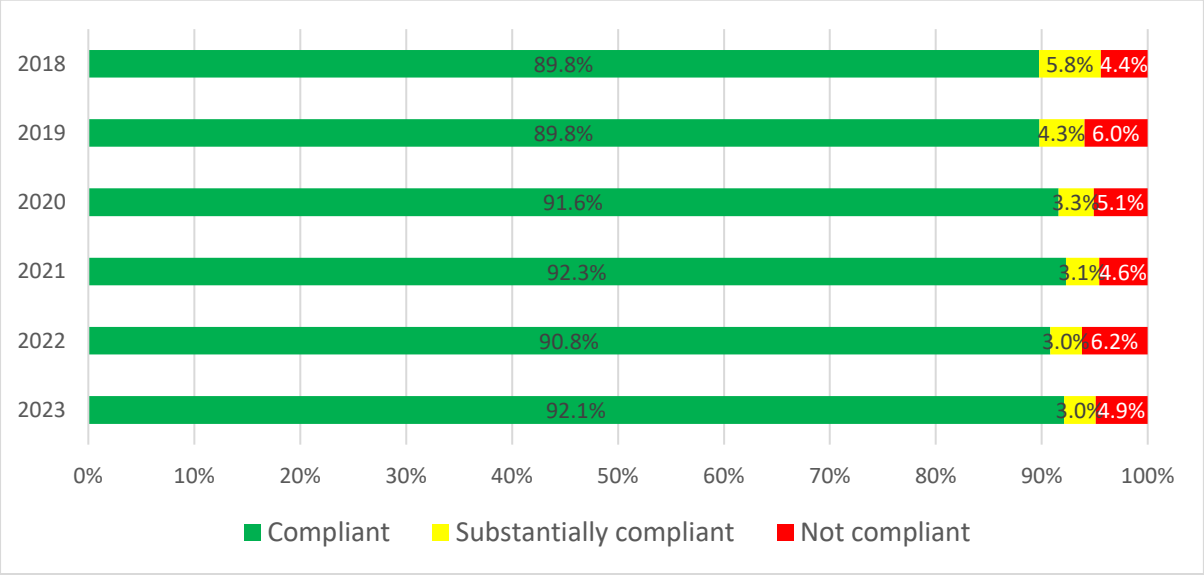
Restrictive practices used in line with the regulations

Psychological support was sought to assist with specific positive behaviour plans and families were also involved in these. There was documentary evidence that the interventions put in place were effective, while at all times promoting a restraint-free environment and protecting the privacy and dignity of the resident. The restraint-free environment was evident from the manner in which the house was designed and on observing how staff and residents interacted.

7.4 Regulatory response and changing culture in centres to restrictive practices

Since regulation began in 2013, the Chief Inspector challenged poor restrictive practices and worked with providers to bring about changes in attitudes and practices. More providers have since put control measures in place such as establishing rights committees for residents, which many providers had already established before regulation started. These committees regularly review the use and application of restrictive procedures. Providers, management and staff are now more aware of what restrictions mean for residents. Figure 15 below shows more recent compliance levels with restrictive practices within the overall regulation on positive behavioural support.[50]

*Figure 15 – Compliance levels with regulation on positive behavioural support**



* Data prior is 2018 is unavailable due to changes in how we assessed compliance. Please also note that the compliance levels in this graph refer only to compliance with the following sub-regulations: 7(4) & 7(5)(a), (b) & (c). This is because these sub-regulations refer specifically to restrictive practices.

Changes in practice and the tighter controls introduced through regulation have resulted in a culture change, despite pockets of poor practice still seen on some inspections and as reflected in the compliance data above. It is now recognised that, fundamentally, restrictive practices are a contravention of a person's basic human rights and should be avoided if at all possible. Nevertheless, there are certain

[50] Schedule 3 of the 2013 care and support regulations also requires records to be kept of the use of restrictive practices, while Schedule 5 requires policies and procedures for such practice.

circumstances where the use of restrictive practices may be necessary, albeit closely monitored and regularly reviewed.

The Chief Inspector has sought to support improvements in this important aspect of care in regulated residential disability centres. Restrictive practices were the focus of our first thematic (quality improvement) inspection programme for disability services in Ireland. This demonstrated the importance of the matter for the Office of the Chief Inspector and made it clear for designated centres that this was a key focus for quality improvement. Ultimately, the goal was to improve the quality of life of people living in designated centres.

Thematic inspections of restrictive practices commenced in 2019[51] after an extensive period of development and stakeholder engagement.[52] While visiting designated centres during these thematic inspections, our inspectors speak with residents to ask if there are things they would like to do that are not allowed to do. They review any documented restrictive practices and interact with staff to understand whether these practices had been necessary and if they had been appropriately managed by staff. They also observe care and the physical premises of the designated centre to determine whether it promotes a restraint-free environment.

As part of the thematic inspection programme, inspectors offer advice and support to providers and staff in designated centres so that they can reduce or eliminate restrictive practices. Below, we look at two examples of how regulation has influenced changes to restrictive practices and how this has greatly improved residents' lives.

How regulation has influenced changes to restrictive practices

Inspection carried out in 2023

There was a clear ethos in the designated centre of minimising the use of restrictive interventions. While there were some restrictive interventions in place, the inspector found that these were the least restrictive necessary in order to ensure the safety of residents and that there was a clear rationale in place for each strategy. There was evidence of restrictions having been removed as soon as safely possible, and several restrictions previously reported in accordance with the regulations had now been removed. In addition, all efforts had been made to offer residents the opportunity to consent to any restrictions.

[51] Between 2019 and the end of 2023, inspectors carried out 153 such inspections, and at the time of writing the programme was ongoing.

[52] https://www.hiqa.ie/reports-and-publications/guide/guidance-restrictive-practice-dcd

Restrictive practices thematic inspection carried out in 2024

The centre had made significant improvements in the reduction or removal of restrictive practices that impacted on the residents. In particular, one resident now had much increased access to different areas of their home.

For example, the kitchen was previously deemed unsafe for them to be present in due to some behaviours they displayed that challenged. With the support from the behaviour therapist, staff members had slowly worked to reduce the kitchen door being locked. The resident now had unlimited access to enter their kitchen space and now enjoyed their meals at their kitchen table. This was a significant step forward for the resident and greatly improved their quality of life and their freedom of movement within their home.

Chapter 8: Safeguarding and protection

8.1 Introduction to safeguarding and protection

Safeguarding means measures which protect the health, human rights and wellbeing of individuals and which enable at-risk adults and children with disabilities to live free from abuse, neglect and harm. Safeguarding is a critically important aspect of residential care and the Chief Inspector is committed to promoting quality improvement in safeguarding across all health and social care services. We will also use the regulations to protect residents of designated centres for people with disabilities, including children, and promote good safeguarding practices.

8.2 Safeguarding and the United Nations Convention on the Rights of Persons with Disabilities

Our focus on safeguarding contributes to improvements with respect to key aspects of the United Nations Convention on the Rights of Persons with Disabilities. Several articles of the convention are relevant in the context of safeguarding:

- Article 14 — Liberty and security of person
- Article 16 — Freedom from exploitation, violence and abuse
- Article 17 — Protecting the integrity of the person
- Article 23 — Respect for home and the family.

Good safeguard practices in centres will reduce the likelihood of harm or abuse.

8.3 Our experience of safeguarding issues

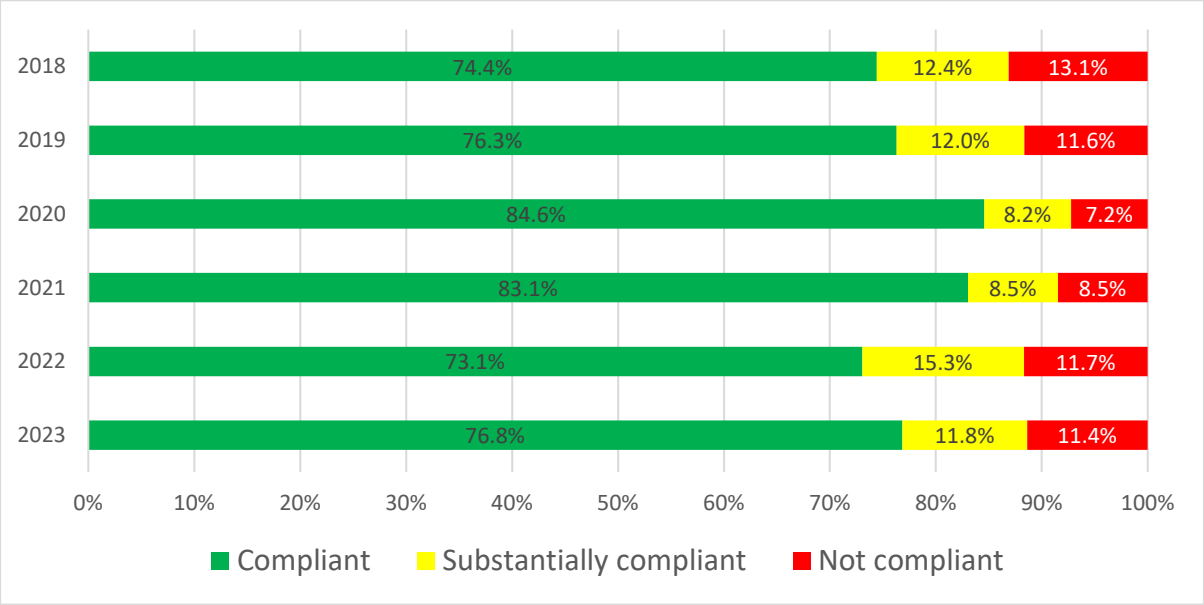
Figure 16 on the next page shows the level of compliance with the regulation on protection and safeguarding over the six-year period from 2018–2023. While there are consistently high levels of compliance with this regulation, there are also persistently high levels of non-compliance (over 11% in both 2022 and 2023).

Non-compliance with this regulation is a significant finding for residents and families, as it may mean that residents are not being fully protected from all forms of abuse. It may mean that the resident's dignity and bodily integrity is not being respected during the delivery of personal intimate care, or that all staff have not received appropriate training in relation to safeguarding residents and the prevention, detection and response to abuse. Where children are resident, it may mean that staff have not received child protection and welfare training in line with government guidance.

Regulation and inspection identify these issues and require providers to manage this risk to residents more effectively. With regular inspection, there can no longer be a situation such as the one that existed in a range of centres at the beginning of

regulation, where poor safeguarding practices and poor responses to suspicions or allegations of abuse can continue indefinitely.

*Figure 16 – Compliance levels with regulation on protection**



* Data prior is 2018 is unavailable due to changes in how we assessed compliance.

Throughout the course of the past decade of regulation, our inspection reports and annual reports have highlighted concerns around safeguarding of residents in designated centres. Abuse incidents may take the form of physical, financial, sexual, psychological or other forms of abuse. All designated centres are required to submit notifications to the Chief Inspector on allegations of abuse and these are followed up by our inspectors.

In disability services, we also observe an ongoing problem of resident-to-resident related issues which are also safeguarding concerns. We also recognise the impact of excessive noise on residents, and pushing and shoving in designated centres. There have also been reports of unwanted teasing.[53]

Residents may have behavioural issues linked to their disabilities that causes them to strike out at other residents. We have long taken a strong position whenever managers and registered providers know about these incidents but fail to keep all residents safe and fail to manage the situation appropriately.

Here are two examples from published inspection reports which typify these kinds of safeguarding issues seen on inspection.

[53] Resident Forums in Centres for People with Disabilities 2021. Dublin: HIQA; 2022.

Example of poor practice related to safeguarding

One resident indicated within the first hour of the inspection that they had been attacked by another resident of the same house and also mentioned the police… Incident reports reviewed also indicated that not all incidents of a safeguarding nature had been notified to HIQA. A second resident living in this house indicated to an inspector that they… did not like it when another resident living in that house said they were going to go into their bedroom, although they said this had not happened. The resident indicated they had not raised this issue with staff. The resident also indicated that they did not like it when the same peer turned off lights in the house.

When asked by an inspector if there was anything else the resident wanted to tell the inspector or show them, the resident brought the inspector to a downstairs toilet in their house. They then told the inspector how sometimes they want to use this toilet but cannot as another resident stops them from using this. They also highlighted how the other resident can open the toilet door while the toilet is occupied… The third resident of this house… said that they did not like it when another resident ran at them. Inspectors found evidence of ongoing safeguarding concerns in this house. For example, in reports, some residents were described as either fearing or being intimidated, by another resident.

Example of poor practice related to safeguarding

The inspector saw that there had been multiple incidents of peer-to-peer verbal and physical abuse recorded in the designated centre. Not all of these incidents had been notified to the Chief Inspector as required by the regulations or to the local safeguarding team. The safeguarding documentation and records in the centre had not been adequately maintained. Many incidents had not been recorded on incident report forms but were typed by staff and stored in a separate folder. Some of these were not signed or dated. This meant that practices around incident recording and reporting were inconsistent. The impact of this was that the provider was unable to adequately assess the frequency and impact of safeguarding events. Residents spoke about the impact of abuse on their wellbeing and described times when they had to isolate in their bedroom or leave the centre due to abuse.

The impact of abuse on the residents was documented by staff, with one resident having informed staff on multiple incidents that they "can't cope anymore". This resident told staff that they were very hurt and that they felt that nothing was being done about the abuse. The registered provider had failed to protect residents from all forms of abuse.

8.4 Managing situations where residents do not get along with each other

Some people, because of their needs or preferences, do not like living with other people and sometimes people may not be compatible living together. From the very start of regulation, the Chief Inspector in HIQA has held the view that providers, managers and staff must appropriately manage situations where people living together do not get along or where there may be peer-to-peer issues, such as bullying, abusive or domineering behaviour. It is not acceptable to operate a service in which there is regular conflict among residents or where residents live in fear of another resident. Neither is it acceptable to allow a culture develop where residents in distress are invisible to staff or seen to be problematic. For this to be allowed as part of the routine operation of the centre is an infringement on the human rights of the residents.

People have a right to safety and security in their own home, and the regulations on protection state the registered provider shall protect residents from all forms of abuse. For many years, there was an accepted culture that resident-to-resident related issues was a part of life in services for people with disabilities. The Chief Inspector rejects this view, and managers and registered providers of designated centres are expected to respond promptly to such issues in order to safeguard all residents.

In its April 2024 report on ensuring rights-based adult safeguarding in Ireland, the Oireachtas Joint Committee on Disability Matters noted in its findings that 'peer abuse is often minimised, ignoring the fact that it is akin to experiences of domestic violence for a resident in a care setting'. Overall, the committee reported a significant gap between what is reported to the HSE services and what may be the reality.[54]

Below, we present short excerpts from inspections reports where regulation has had a positive effect on safeguarding practices in a service. In 2015 and 2016, the provider had failed to demonstrate that residents were being protected from all forms of abuse as residents were at risk of harm from their peers. A notice of proposed decision to cancel the registration of the centre was issued in 2016 but was later withdrawn by the Chief Inspector. The provider reduced the capacity of the centre from three residents living there to one, reconfigured the space and went on to provide a good quality of life for the resident.

[54] Joint Committee on Disability Matters. Ensuring rights based adult safeguarding in Ireland: April 2024.

Example of where regulation has had a positive effect on a service	
Inspection of service in 2015	**Inspection of same service in 2021**
The rights and safety of residents were not protected in a satisfactory way. Inspectors found that the mix of residents in the centre did not ensure that all residents were protected from injury and harm by their peers. It was evidenced that individual residents did not feel safe in the centre. Due to the level of risk identified and the impact on individual residents, the provider was required to take immediate action and submit a plan to the Authority as to how the situation would be resolved. The provider responded in an appropriate manner within the agreed timescale to mitigate the immediate risk and seek a solution within a reasonable time frame.	The designated centre reduced the number of residents living in this designated centre in 2019 and staff reported increased wellbeing as a result of this move. On arrival to the centre, inspectors were warmly welcomed by the resident who invited the inspectors into their home and prepared tea. The resident was then observed to enjoy table top activities before guiding the inspectors around their home… There were systems in place for safeguarding residents. The inspector reviewed a sample of incidents which demonstrated that incidents were reviewed and appropriately responded to.

8.5 Broadening the scope of safeguarding

In the absence of adult safeguarding legislation and in collaboration with the Mental Health Commission, HIQA developed and published the nation's first *National Standards for Adult Safeguarding* in 2019.[55] These standards are divided into eight themes (areas of care) and describe how designated centres can promote care and support that proactively protects people.

Our emphasis on safeguarding is not simply about protecting people from abuse. We also wish to broaden the scope of safeguarding to include considerations of how best to promote people's choices and preferences and how to support people to live a fulfilling life and a self-determined life. This means working with residents of designated centres to understand how they want to spend their days, identify plans or goals for themselves, and work towards achieving these in a collaborative fashion.

[55] National Standards for Adult Safeguarding (2019); link

8.6 Vigilance about potential sexual abuse

In its April 2024 report on ensuring rights-based adult safeguarding in Ireland, the Oireachtas Joint Committee on Disability Matters said while 51,000 concerns about the abuse and neglect of adults have been reported to the HSE Safeguarding and Protection Social Work teams since 2015, it is unknown how many relate to people with disabilities. However, the Committee said 143 alleged sexual assaults against residents of care settings had been reported to the Chief Inspector from 2015 to 2022; 87 of these assaults were in nursing homes where many people with disabilities live and 56 cases were in disability centres. The committee made a number of recommendations, including urgent safeguarding legislation and increased powers for the Chief Inspector within HIQA.[56]

Occasionally, inspectors have concerns about how providers manage residents' sexual expression in centres, as set out in this inspection report:

Example of the poor management of sexual expression

The inspector observed one of the residents on the couch engaging in inappropriate sexual behaviour, which was not responded to by agency staff who were supporting them… The provider had a programme of staff training in the centre. Inspectors were told that staff had completed training in a number of areas: these included communication skills, emergency medication administration, CPR and emergency responder training. However, training records were not up-to-date and not all staff had completed training in positive behaviour support and supporting residents' sexual expression which was essential due to the highlighted risks at the centre…

8.7 Promoting safeguarding in services

A national safeguarding committee was established by the HSE in December 2015 in the aftermath of adult abuse issues within a designated centre in the West of Ireland. In 2017, the national safeguarding committee evolved into an independent entity, National Safeguarding Ireland CLG, which is a registered charity trading as Safeguarding Ireland.[57] A core objective of Safeguarding Ireland is the introduction of adult safeguarding legislation. We will look at this issue later in this chapter. In the interim of such legislation being introduced, we have worked with others on

[56] Joint Committee on Disability Matters. Ensuring rights based adult safeguarding in Ireland: April 2024.

[57] Safeguarding Ireland Chairperson Patricia Rickard-Clarke to Joint Committee on Disability Matters debate, 21 February 2024.

developing national safeguarding standards for adults and associated tools to promote safeguarding in services.

8.7.1 National Standards for Adult Safeguarding

In the autumn of 2019, the Minister for Health approved the *National Standards for Adult Safeguarding*, jointly developed by HIQA and the Mental Health Commission and published in December 2019. The national standards recognise the right of every adult to be safe and to live a life free from harm. Approval by the Minister for Health places a responsibility on all residential services for people with disabilities to begin implementing them.[58] The standards are designed to apply to all health and social care services, including residential services for people with disabilities. While the Chief Inspector can inspect against these standards, the aim of the safeguarding standards is to support services to improve their practice and to promote people's rights, health and wellbeing and reduce the risk of harm.[59] The Chief Inspector intends to carry out focused regulatory inspections on adult safeguarding in 2024 using both the regulations and national standards — with a view to promoting this aspect of care and support in designated centres and encouraging quality improvements that will ultimately benefit residents.

8.7.2 Advocating for safeguarding legislation

Over the years, we have used our regulatory powers and inspection reports to push for registered providers to embed a culture of safeguarding into their services. In addition, HIQA and the Chief Inspector have long been calling for adult safeguarding legislation,[60] including when our former CEO, Phelim Quinn, told the 2016 MacGill Summer School that, "This is unfortunately another area where Ireland has been slow to respond. It has been a neglected issue over the years, and legislation and guidance is now long overdue."[61]

In October 2022, senior HIQA staff appeared before the Oireachtas Joint Committee on Disability matters, with the Chief Inspector telling the meeting: "It is hugely important to bring in safeguarding legislation, not just for those living in designated centres but for any vulnerable adult."[62] HIQA has advocated for the introduction of safeguarding legislation that can work alongside the Health Act 2007, the regulations

[58] Frequently asked questions (FAQ) about the National Standards for Adult Safeguarding. Dublin: HIQA and Mental Health Commission.

[59] Ibid.

[60] HIQA Submission to the Committee on the Future of Healthcare, 10 March 2016.

[61] Speech by former HIQA CEO Phelim Quinn to the MacGill Summer School, 21 July 2016.

[62] Chief Inspector speaking at the Oireachtas Joint Committee on Disability Matters, 27 October 2022.

and the Assisted Decision-Making (Capacity) Act 2015, which was fully commenced in 2023.

8.7.3 Safeguarding measures in the absence of legislation

While we do not yet have safeguarding legislation, the Chief Inspector is committed to using the current regulatory framework to minimise risk for people living in designated centres (see case studies above). Providers must ensure that their staff are able to recognise and report any suspicions of abuse, and that residents are empowered to do the same. When suspicions are reported, providers must have measures in place to prioritise the protection of residents and to investigate these allegations effectively and in a timely manner. Our role is to examine the safeguarding measures in place to ensure they are working, and to require the provider to improve them when they are inadequate.

8.7.4 Limitations of regulations in relation to safeguarding

When the *Guidance on upholding Human Rights in Irish health and social care settings* was published in late 2019, Safeguarding Ireland said legislation was urgently needed to underpin it. The HSE's National Safeguarding Office has reported that the HSE has invested in strengthening safeguarding services and is focused on service improvement by implementing the HSE Patient Safety Strategy as well as using learning from safeguarding internal audits, national review panel findings and inspection reports published on the HIQA website.[63] Sharing learning in this regard is to be welcomed, but while there are disability regulations around safeguarding, we believe they do not go far enough to protect vulnerable adults.[64]

Recent years have highlighted the need for new legislation to support the registration of designated centres in an emergency, to ensure that no resident who requires a residential placement is at risk of being placed in accommodation that is outside the current protection of the Health Act 2007, as amended. The Chief Inspector continues to engage with Government Departments in addressing this significant gap in the legislation and will welcome any future reform to the Act and the regulations which will afford residents this protection. New legislation, such as the Assisted Decision-Making (Capacity) Act (2015), will impact on how people with disabilities living in registered centres can access their rights and exercise choice.

Strong and effective adult safeguarding legislation is now required to protect the most vulnerable in our communities. We will continue to engage with the

[63] HSE National Safeguarding Office Annual Report 2022, page 8.

[64] Chief Inspector speaking at the Oireachtas Joint Committee on Disability Matters, 27 October 2022.

Department of Health and the Department of Children, Equality, Disability, Integration and Youth to support the development of safeguarding legislation, and to update the Health Act 2007 as amended and associated regulations so that they continue to provide protection for people with disabilities and reflect changes in the legal landscape, including the implementation of the UNCRPD.[65]

[65] Opening Statement by the Chief Inspector to the Oireachtas Joint Committee on Disability Matters, 31 March 2022.

Chapter 9: General welfare and development

9.1 Introduction to general welfare and development

In the early days of regulation, many providers used a more risk-averse and medical model of care and support, with many institutionalised practices in place, particularly in congregated settings. Regulation has helped re-shape the approach taken by providers to one that is more person centred and informed by human rights principles. This chapter focuses on the theme of 'general welfare and development' and highlights some examples of where residents are being supported to live full and active lives. General welfare and development is about each person being supported to develop and maintain their sense of worth, and personal relationships and links with the community in line with their wishes. It is also about providing opportunities for relaxation, activities, education, training and employment that promotes their independence, strengths, abilities and individual preferences.

9.2 United Nations Convention on the Rights of Persons with Disabilities and general welfare and development

Our focus on promoting the general welfare and development is in line with several articles under the UNCRPD. These include:

- Article 9 — Accessibility
- Article 19 — Living independently and being included in the community
- Article 24 — Education
- Article 23 — Respect for home and the family
- Article 26 — Habilitation and rehabilitation
- Article 28 — Adequate standard of living and social protection
- Article 30 — Participation in cultural life, recreation, leisure and sport.

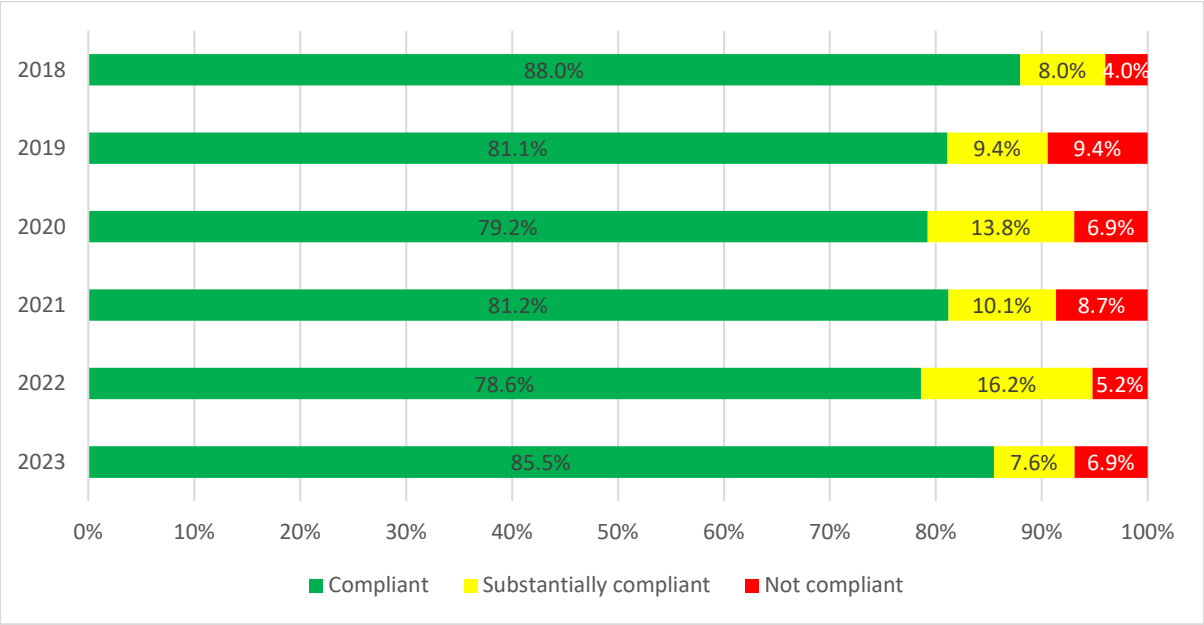
Supporting people's general welfare and development means that residents are supported to become active members in their community and to keep connected to family in line with their wishes. It also ensures that residents are provided with opportunities for education and meaningful activities.

9.3 Our experience of general welfare and development

Figure 17 shows compliance levels with the specific regulation on general welfare and development between 2018 and 2023. The regulation is broad in scope, and includes the registered provider giving each resident appropriate care and support in line with evidence-based practice. It also covers the provision of occupation and recreation, opportunities to participate in activities in accordance with the residents' interests, capacities and developmental needs; and being involved in the wider community. There are also sub-regulations to ensure children have opportunities for play, age-appropriate opportunities to be alone, and opportunities to develop life

skills, among other minimum legal requirements around education, training and employment and where residents are moving between services. Overall, there has been good compliance, but non-compliance can have a significant impact on residents' quality of life. In this chapter, we will look at some examples of both good and poor practices in the area of general welfare and development.

*Figure 17 – Compliance levels with regulation on general welfare and development**



* Data prior is 2018 is unavailable due to changes in how we assessed compliance.

9.4 Overall general welfare and development

One of the best ways to consider the overall general welfare and development of residents in designated centres is to consider the difference in quality of life between those who live in large congregated settings and those who live in regular houses in the community. In short, our experience of the impact of regulation is that people living in the community have a better quality of life. Those living in larger settings — many of whom are still leading largely regimented and controlled lives — continue to experience care that inhibits their choices and preferences and that is not always delivered in a person-centred manner.

9.4.1 Congregated settings versus community living

Congregated settings are places where 10 or more people live together or are based in a campus-style setting. As mentioned elsewhere in this report, the outcomes for people living in congregated settings are not as good as for those who live in smaller, community settings. For example, in these two inspections from 2019 and 2021, we found many residents were still receiving institutionalised care largely based on historical care practices, the staffing roster and routine of the staff. In

these two centres, residents had little contact or engagement with the outside world, had limited opportunity to develop their independence and were leading limited lives.

Poor outcomes for residents of a congregated setting — 2019 inspection

Through the review of documentation and discussions with staff, there were identified compatibility issues between a number of residents living in the centre. The provider had recognised this and there were a number of residents identified to transition from the centre due to this, or in line with their changing needs. However, these transitions were not progressing in a timely manner with one resident waiting three years to transition in line with their wishes and preferences. The inspectors acknowledge that this resident had been supported to access an advocate to support them and that a referral had been made to the Office of the Ombudsman.

Poor outcomes for residents of a congregated setting — 2021 inspection

The design and layout of the designated centre was not suitable due to the lack private space available for the majority of residents who lived in dormitory-style accommodation. In addition, improvements were required in relation to the monitoring and oversight of care and support for residents particularly relating to, infection prevention and control, risk management, staffing, and staff training.

Our inspectors have encountered many examples where registered providers have worked with residents and their families to transition out of congregated settings and into smaller homes with individualised plans. This is often a slow process but this is understandable as it is more important that it is done right as opposed to done quickly. Residents should be central to any discussions on decongregation and should play an active role in the selection and design of their new homes. Our inspections have shown that once residents move to a regular house in the community with appropriate support available to them, their quality of life dramatically improves, not only in terms of the physical fabric of the centre but also in the lives people lead and the independence they gain.

Our inspection reports contain multiple examples of improved outcomes for people who move from congregated settings into houses in the community. The following is an excerpt from a report that illustrates the improvements.

Improved outcomes for residents who move into the community — 2023

Some residents spoke to the inspector about their move to the centre in 2016 from a large congregated setting. Due to the nature of the congregated setting,

they lived with many other residents, resulting in a busy and loud environment. Residents described their previous home as being located far away from community facilities, and they did not always have the choice to leave the centre. Residents told the inspector they had been supported to move into community-based homes by the provider and had viewed a number of houses before deciding upon this location. The inspector was told by the residents that they loved their home, enjoyed spending time with each other and were very complimentary of the staff team.

Residents were empowered to engage in positive risk-taking to exercise choice and take risks to achieve outcomes that were important to them. These included independent public transport travelling, self-administration of medicines and international travel. In addition, some residents did not always require the support of staff and could stay in their homes in the absence of staff for periods of time.

9.5 Change in culture seen since regulation began

We have found that an old-fashioned, paternalistic viewpoint that some registered providers held is not as prevalent as it was in the early years of regulation. When we started regulating services in 2013 we observed many institutional practices, such as settings being overly clinical in nature, residents' personal information being posted on walls, and services being delivered on the basis of the work patterns of staff rather than on the needs of residents. Underlying this was a prevailing sense on behalf of some registered providers that theirs was a charitable role, typified by a risk-averse and medical model of care.

Changing the culture to where care is delivered in a more person-centred manner took time and patience. Some registered providers could not adapt to this model of care and ceased operating. However, broadly speaking, the majority have now embraced a more social model of care that is informed by human rights principles. Below are some examples that describe how the provision of care has evolved over the past decade of regulation.

Examples of how the provision of care has improved since 2013

Case study — Tommy's story

As part of our 2021 Resident Forums where we engaged with people with disabilities living in designated centres outside of the inspection process, we published *Tommy's story* on our website. His experience illustrates an example of where residents have been empowered to undertake activities or engage in

positive risk-taking or other innovative ways to help them become part of their communities.

Tommy moved from a congregated setting to a community-based setting and wanted to tell his story. He moved from a highly restrictive environment living with over 20 other residents to fully immersing himself in the community, and living with four other residents. His favourite activities including socialising with friends in his local pubs and visiting the bookies, using public transport and owning a pet for the first time. This is a little of what Tommy told us.

> Hi. My name is Tommy. This is my home. This is my cat, Guinness. I choose what I want to do every day. I look after my cat every day and paid for him to be neutered and get a check-up. I painted my cat's home by myself. I save money every Wednesday independently in my local post office. My new business plans! I paint and upcycle furniture. I sell it when I am finished. My local pubs. I go here by myself and meet my friends. This is my local bookies. I go here by myself, place bets and socialise. I saved up and bought a smart phone. I keep pictures of my family and my cat on it and know how to look at the pictures.

You can view Tommy's story in full on www.hiqa.ie.

Case study — love of cars

How a provider facilitated a resident to continue their love of cars following an acquired brain injury also illustrates an example of where residents have been empowered to engage in positive risk-taking or other innovative ways to help them become part of their communities. A provider in the northeast of the country provides a full-time residential service for five adults who present with

intellectual disabilities, autistic spectrum disorder, and or acquired brain injuries. The provider supported a resident to purchase a car, which was being modified so that the resident can travel in it. The resident had a keen interest in motorsports, and, along with staff members, attended motor shows. The inspection report noted:

> The provider and staff team supporting the residents focused on developing skills in self-determination and decision-making. The inspector reviewed a sample of residents' daily notes and found that they were engaged in things they wanted to do for; example, some residents were completing financial management and computer courses after identifying this as a goal. Another example was that a resident who had a keen interest in motorsports was supported to purchase their preferred car using their personal funds. The car was due to be modified to aid the resident when travelling in the vehicle. In summary, the provider and the team supporting the residents did so in a person-centred manner. Residents were encouraged to take the lead in all aspects of their lives, and if required, the staff team were there to support them. The regulations reviewed during the inspection were found to be fully compliant.

Case study — residents leading active lives

Another example of residents being empowered to live active lives was seen in a designated centre located in a busy Dublin suburb. This was observed during a 2023 thematic inspection of restrictive practices, where the provider was found to be compliant when assessed against the national standards. All staff had received training in human rights, and the provider had a human rights committee. From what the inspector observed and what residents and staff communicated, this training was used to enhance the care and support provided to residents. The inspection report stated:

> Residents were observed to have busy and active lives. The inspector had the opportunity to meet with some of the residents on the day of inspection. The residents from one of the houses had plans for the evening and met staff directly after their day services to go for a meal and to the cinema after. The residents from the other house were on the way out the door to go swimming when the inspector arrived. One of the residents communicated where they were going by showing the inspector his swimming bag and a music CD he was bringing to listen to on the way. Some of the residents had plans to attend a disco a later on that evening organised by the provider… Each resident's personal plan promoted positive risk taking and engagement in the residents' local community. For

example, one resident was supported to engage in and attend paddle boarding classes at the local harbour.

Chapter 10: Current and future challenges for the sector

10.1 Introduction to current and future challenges

This report has charted the journey of regulation over the past 10 years in residential disability services in Ireland. The introduction of regulation was challenging for many registered providers but the majority have responded to that challenge and have sought to move beyond basic regulatory compliance and are seeking to embed a culture of ongoing quality improvement in the way care and support are delivered to people with disabilities in their designated centres. However, as this report shows, further work is required to ensure all residents have the opportunity to live full lives.

When regulation commenced in late 2013, there was much that was good about care practices in centres, with many providers delivering good or excellent care and support to residents. Despite this, there was also a significant cohort of centres where there was a significant risk to the safety of residents and where residents were experiencing a very limited quality of life. Often, the care practices were regimented and institutional, and were ineffective at safeguarding residents. In most cases, poor and institutional practices and cultures had been perpetuated and had gone unchecked for many years.

Regulation has provided an effective way for the State to identify and challenge poor practices that sometimes emerge in residential centres, and to promote the human rights of residents. The Chief Inspector believes that regulation ensures that poor practices are challenged in a timely manner and do not become embedded in services, as had happened before regulation started in 2013.

As the regulator, our approach has changed as we have sought to be proactive in how we fulfil our role. The provision of good quality health and social care is ever evolving. When we look back on how care was provided in the past, we may regard some practices as antiquated and, often, inhumane. Equally, a person reading this report in 100 years' time may regard care provided in the early 21st Century in the same fashion. That is why there must be a committed effort by all stakeholders to strive for ongoing quality improvement in how care is provided and how people are supported.

This section of the report will discuss current and future challenges in the disability sector in Ireland with a view to making a contribution to the conversation on how we can modernise the country's services and deliver the best care possible for citizens.

10.2 A vision for social care

There is currently no overarching social care policy or legislation in Ireland that sets out a vision for how people should be cared for and supported into the future. HIQA

welcomes the Department of Children, Equality, Disability, Integration and Youth's Action Plan for Disability Services 2024–2026 which is a strategy that looks to reform the model of service delivery in the disability sector. This is a welcome intervention by Government and our view is that this should be a starting point for wider reform and a more comprehensive strategy encompassing all of social care.

As a country, such a wider approach to social care delivery could contribute to a public discussion on what kind of care and support services we want to have for people who are older, people with disabilities and others that need support. Such a vision should include the models of service delivery, how services will be funded, operated, staffed and monitored so that all citizens can be assured we have a social care system that is fit for its intended purpose.

10.3 Legislative and regulatory gaps

Despite huge improvements in the safety and quality of designated centres for people with disability arising from regulation, we have previously highlighted the need to reform the Health Act 2007 and associated regulations, which we believe are not sufficiently underpinned by a human rights-based approach. For example, the Act contains a narrow definition of a designated centre which limits the regulatory protection of people with a disability to the confines of the centre's footprint. We have highlighted to the Oireachtas the need for a broader definition that takes a more holistic view of the supports that people with disabilities require, providing them with greater protection and enhancing their quality of life.[66]

In June of 2020, HIQA formally requested that the Minister for Health, through his department, review and strengthen components of the Health Act and associated regulations governing the operation of designated centres.[67] The Chief Inspector has been working closely with the Department of Health around some of the limitations of the current regulatory process.[68] Some changes to legislation have been signed into law.[69] For example, the Health (Miscellaneous Provisions) (No. 2) Act 2024, when commenced, proposes to amend the Health Act 2007 to give an additional power to the Chief Inspector to issue a compliance notice to providers, which in effect would be a statutory requirement to take specific measures. This is a welcome addition to the powers of the Chief Inspector as it would allow a statutory means by

[66] Opening statement by the Chief Inspector to the Oireachtas Joint Committee on Disability Matters, 31 March 2022.

[67] HIQA News, 9 December 2020, Issue 40.

[68] HIQA CEO Angela Fitzgerald speaking at the Oireachtas Joint Committee on Health, 4 October 2023.

[69] Health (Miscellaneous Provisions) (No. 2) Act 2024.

which to engage in early intervention for poorly-performing designated centres. The timelines for providers to consider the decisions of the Chief Inspector will also be reduced once the relevant section of the Act is commenced in order to for these decisions to take effect more quickly.

Other proposed changes include:

- providing a clear legal basis for the Chief Inspector to enter and inspect a premises which is unregistered, if the Chief Inspector has reasonable grounds to believe that the business of an unregistered designated centre is being carried on
- providing an express power for the Chief Inspector to remove a condition attached to registration of a designated centre without an application from the registered provider.

The Chief Inspector welcomes these amendments and will continue to support further enhancements to the regulatory framework.

10.3.1 Definition of a designated centre

The current definition of a designated centre works well for services that are owned or leased by a registered provider that also provides the care and support to the residents. More recently, there have been examples of living arrangements where a person's accommodation is provided directly to residents by a third party such as an approved housing body or private landlord. Such arrangements have arisen as solutions to housing demand in local areas but these pose a challenge with respect to meeting the definition of a designated centre. As a consequence of the changing landscape, the Chief Inspector published updated guidance on this matter in 2022 entitled *What is a designated centre?*. This guidance assists residents and registered providers in determining whether their living and care arrangements should be considered designated centres. The guidance is available on www.hiqa.ie.

10.4 Capacity in residential disability services

As the Chief Inspector advised the Oireachtas Joint Committee on Disability Matters in 2023, there is insufficient residential capacity in the system. In the Committee's pre-Budget submission published in June 2024, the Committee said it believes that there is an urgent need to create equity in the system and it recommended redistribution of funding in Budget 2025 in line with the UNCRPD to deliver better outcomes for people with disabilities, and maximise people's capacity, independence,

and quality of life.[70] We welcome this recommendation. In our experience, many adults and children who are in crisis are not able to access placements near home and many must sometimes move quite a distance. That is traumatic because when they are in crisis, they are leaving behind people who they know and are going to a strange place with new people providing care and support. This adds to the trauma experienced not only by residents but also by their families.[71]

We are regularly requested to respond to situations where organisations must provide a service to a person in an unregistered centre because they do not have the time to make an application and have that service registered. Whether it is children or adults who are in crisis, the reason for having to take emergency action is that the conditions are unsafe for them or others around them. Often, the service is required that day. It is widely recognised that there is insufficient capacity in disability services currently to enable planning for such circumstances. Moreover, as the regulator, the Chief Inspector has no power to register what might be termed 'emergency placements' and this inhibits our ability to respond in crisis situations. Work had commenced with the Department of Health on emergency registration provision prior to responsibility for disability transferring to the Department of Children, Equality, Disability, Integration and Youth. We are engaging with the Department of Children, Equality, Disability, Integration and Youth to progress amendments to address this gap, the aim being to allow for the emergency registration of services so children and adults can be protected.[72]

10.5 Housing market conditions and impact on decongregation

The ongoing shortage of housing nationally has impacted on the ability of registered providers to source suitable accommodation for residents who wish to live in smaller settings in the community. Providers have informed us that one of the reasons that a number of planned moves from congregated settings have slowed down is because of a shortage of appropriate housing. This is negatively impacting on people's quality of life as they cannot live in communities of their choosing. As mentioned elsewhere in this report, there is a need for a national vision and strategy for how social care should be delivered in Ireland. Suitable accommodation and the needs of people with disability should be central to this strategy. We welcome the

[70] Joint Committee on Disability Matters. Aligning Disability Funding with the United Nations Convention on the Rights of Persons with Disabilities: Budget 2025 Pre-Budget Submission June 2024.

[71] Chief Inspector speaking at the Oireachtas Joint Committee on Disability Matters, 8 November 2023.

[72] Deputy Chief Inspector (Disabilities) at the Joint Committee on Disability Matters, 8 November 2023.

June 2024 pre-Budget recommendation from the Oireachtas Joint Committee on Disability Matters that 'Long term planning and funding harmonisation between Department of Health and Department of Housing, Local Government and Heritage is required to support the move away from institutionalism and provide rights-based care to disabled people and the elderly to ensure long term sustainability of care.'[73]

10.6 Other legislative changes and policy measures

Recent and forthcoming policy and legislative changes are likely to have a significant impact on how people with disabilities can access their rights and exercise choice. The Assisted Decision-Making (Capacity) Act 2015 is one such piece of legislation. This Act was fully commenced in 2023 and includes a range of measures to support people who may need help with making decisions. Previously, there was a reliance on very old and outdated legislation which effectively meant that people had little say in how they lived their lives if they had difficulties with capacity. The new legislation provides a mechanism where people with a range of different decision support needs can enter into formal arrangements.

The task now is to ensure that all people living in residential care can access these rights and appoint people to support them with important decisions about their lives if they so wish. This may present challenges to registered providers, particularly where a person indicates that they wish to make changes to their living circumstances or care arrangements. While HIQA has no statutory role in monitoring the implementation of the Assisted Decision-Making (Capacity) Act 2015, we will work with registered providers to ensure that residents in designated centres are facilitated to access their rights under this important legislation.

As referenced elsewhere in this report, safeguarding is a key focus for the Chief Inspector in the coming years. The introduction of adult safeguarding legislation has been in development for a number of years and is supported by other stakeholders such as Safeguarding Ireland, the Law Reform Commission and the Oireachtas Joint Committee on Disability Matters. A range of legislative and policy measures have been in place in Ireland for many years to promote the welfare and protection of children. However, specific legislation to safeguard adults at risk of harm is long overdue and, when introduced, will place additional responsibilities on all those involved in the provision of health and social care services.

[73] Joint Committee on Disability Matters. Aligning Disability Funding with the United Nations Convention on the Rights of Persons with Disabilities: Budget 2025 Pre-Budget Submission June 2024.

10.7 Conclusion

This report has set out the developments and changing culture in the residential disability sector over the past decade. 2013 presented many challenges for services. The lingering effects of the financial crisis in Ireland meant that very little funding was available for investment in services in the early years of regulation. Many residents were living in outdated and poorly maintained buildings that were institutional in nature, while the culture in some services was paternalistic and the care regimented. Many services were not promoting person-centred care. While many residents were already experiencing good quality and excellent care by committed providers, other residents were not being enabled to live fulfilling lives, did not feel safe, had limited choices and were not engaged in their community. The goal of regulation is to support these people to live a life of their choosing and to be cared for in a respectful and dignified manner.

Much has changed and evolved in the past decade, and many providers have led this change. A more positive staffing culture has emerged in many provider organisations, one that prioritises a human rights-based approach to care. Residents are living more active lives, and staff in services are supporting them to be more active in their communities and to undertake activities of their choosing. Initiatives such as the Assisted Decision-Making (Capacity) Act 2015, the guidance on a human rights-based approach to care and the *National Standards for Adult Safeguarding* are providing a framework that underpins residents' rights and promotes their wellbeing. Many providers are undertaking continual quality improvement initiatives to enrich their services and stretch beyond basic compliance with the regulations. Ultimately, all of this is contributing to better lives for residents using services.

Notwithstanding the above, as the regulator, there is no room for complacency. The Chief Inspector within HIQA must be vigilant and continue to listen to the voices of residents and their advocates. The Chief Inspector will challenge poor practice where we find it and will take action where necessary to benefit residents. The Chief Inspector will continue to make the case for reforms, both to our health and social care systems and to our regulatory framework. HIQA and the Chief Inspector look forward to playing our part in improving the lives of people with disabilities into the next decade. As the sector continues to develop and grow, we will continue to work closely with all our partners — the Minister for Health, Minister for Children, Equality, Disability, Integration and Youth, officials and ministers of State in government departments, those using health and social care services, residents, families and advocates, health and social care professionals, and providers — to plan for the resources needed to maintain the ongoing effective regulation of residential services for people with disabilities.

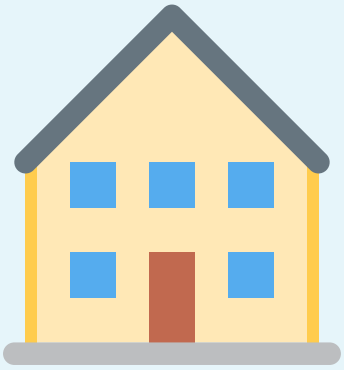
2023 Overview

Health Information and Quality Authority
An tÚdarás Um Fhaisnéis agus Cáilíocht Sláinte

Regulation of Disability Services

Number of Centres

1,574
designated centres
+96 since 2022



9,147
residential places
+117 since 2022

Congregated settings*

212
+11 since 2022

2,256
residential places
-23 places on 2022

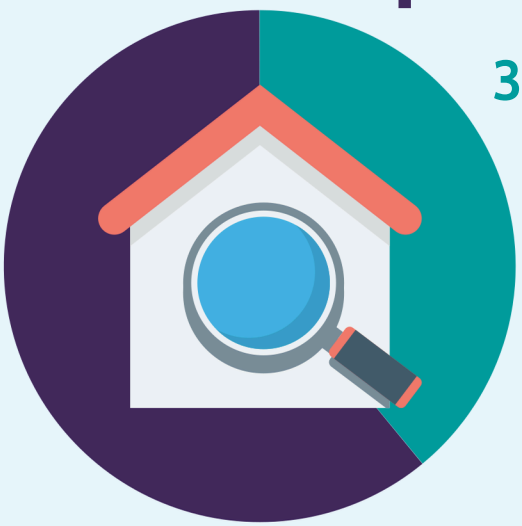
Respite centres

152
+1 centre on 2022

732
respite places
-6 places on 2022

*Congregated settings are centres where more than 10 people live in the same building or in a group of buildings which are located together on campus. The increase in these settings is due to providers dividing existing large centres into multiple small centres.

1,268 Inspections



39% announced inspections

61% unannounced inspections

Repeat inspections

136 centres had two visits

10 centres had three or more visits

Receipt of information

29,419 notifications from services

327 pieces of unsolicited information (received from the public)

We welcome information from the public about their experiences of social care service.

Registrations

- **121** new centres registered
- **377** registrations renewed
- **384** applications for conditions of registration to be varied

Notice of proposed decisions

8 centres issued a Notice of Proposed Decision (NOPD) to cancel

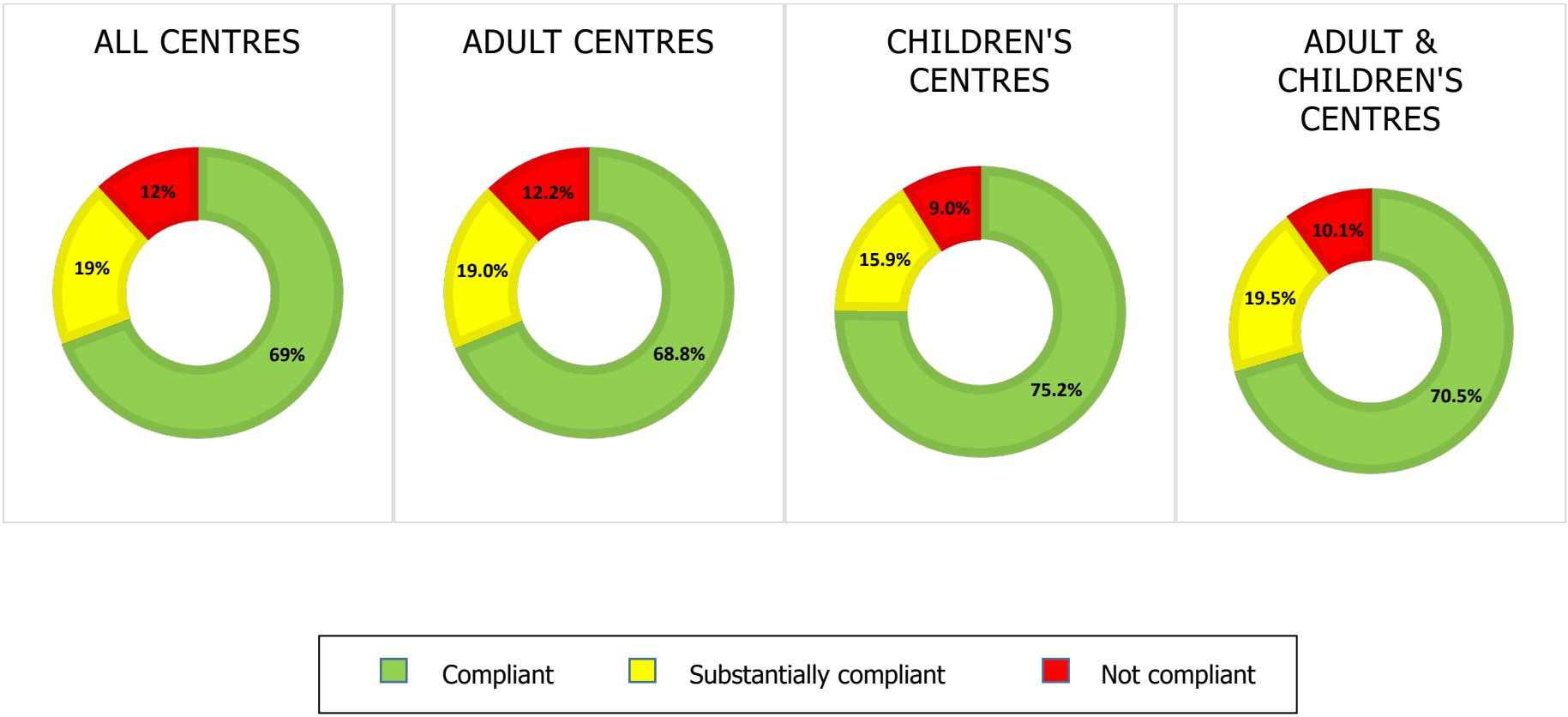
1 centre was issued a Notice of Decision to cancel registration and alternative arrangements were put in place by HSE

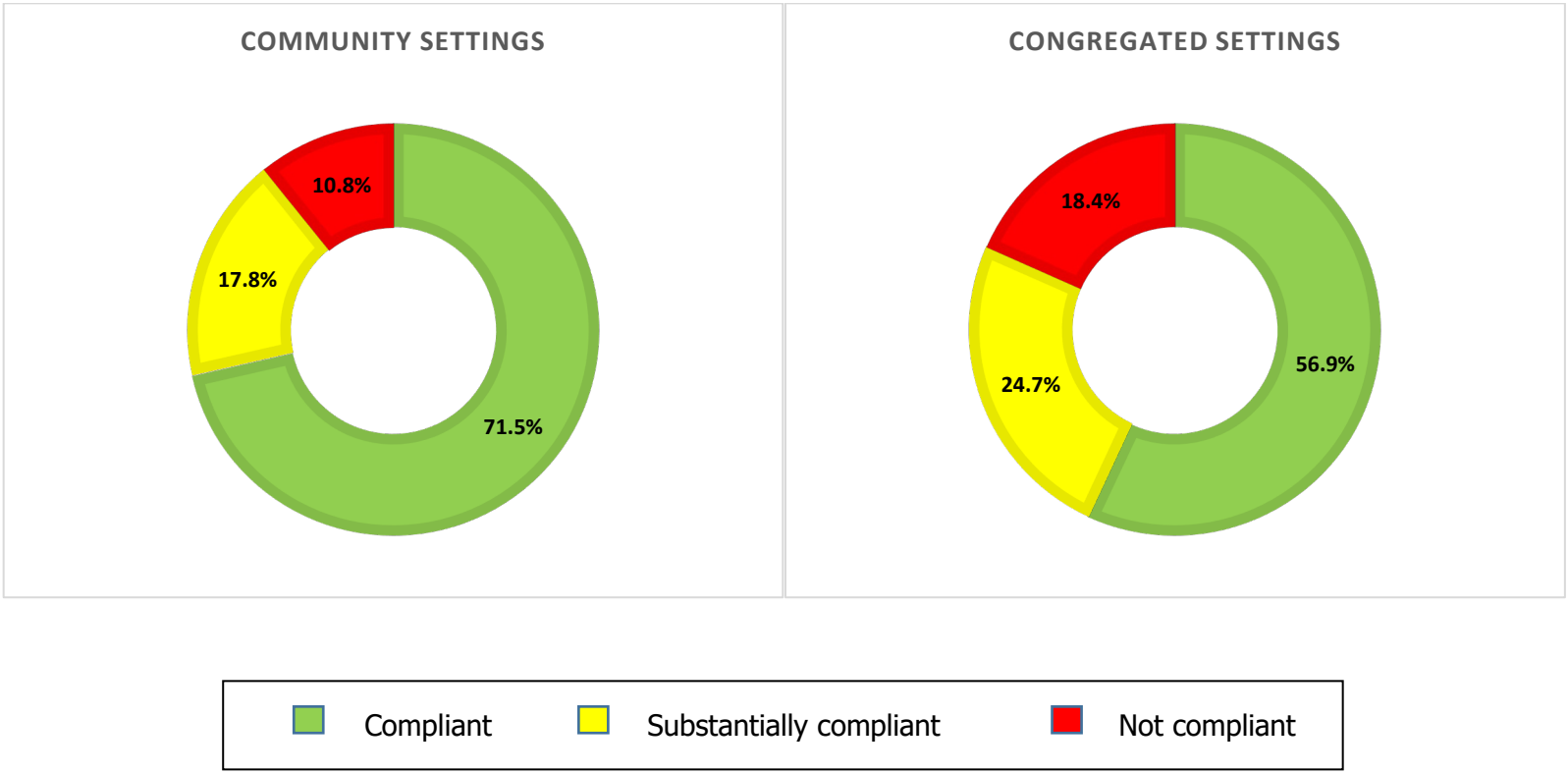
2 centres were issued an NOPD to refuse

2023 Compliance Data

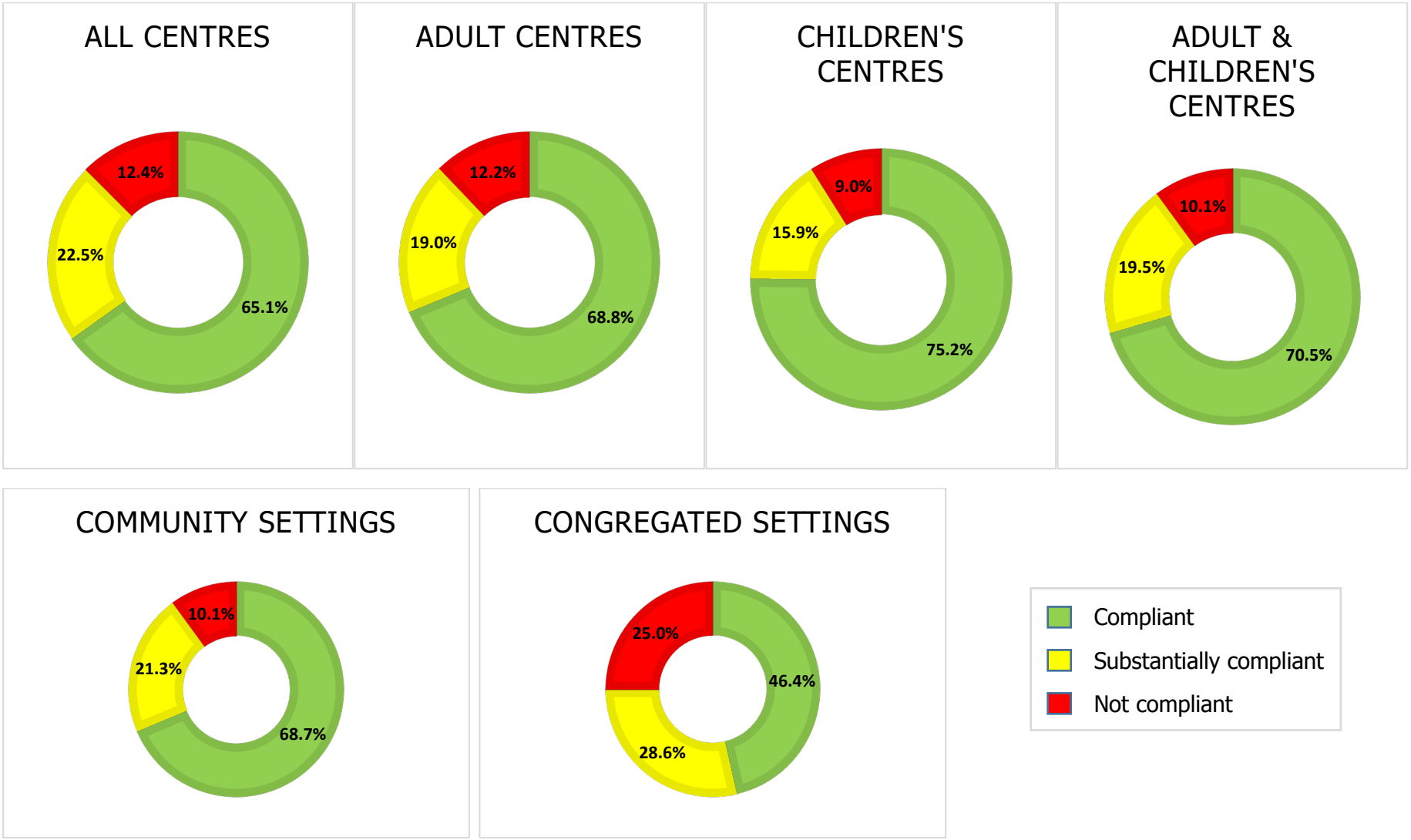
The following series of graphs describe the level of compliance observed in designated centres for the year 2023.

All regulations

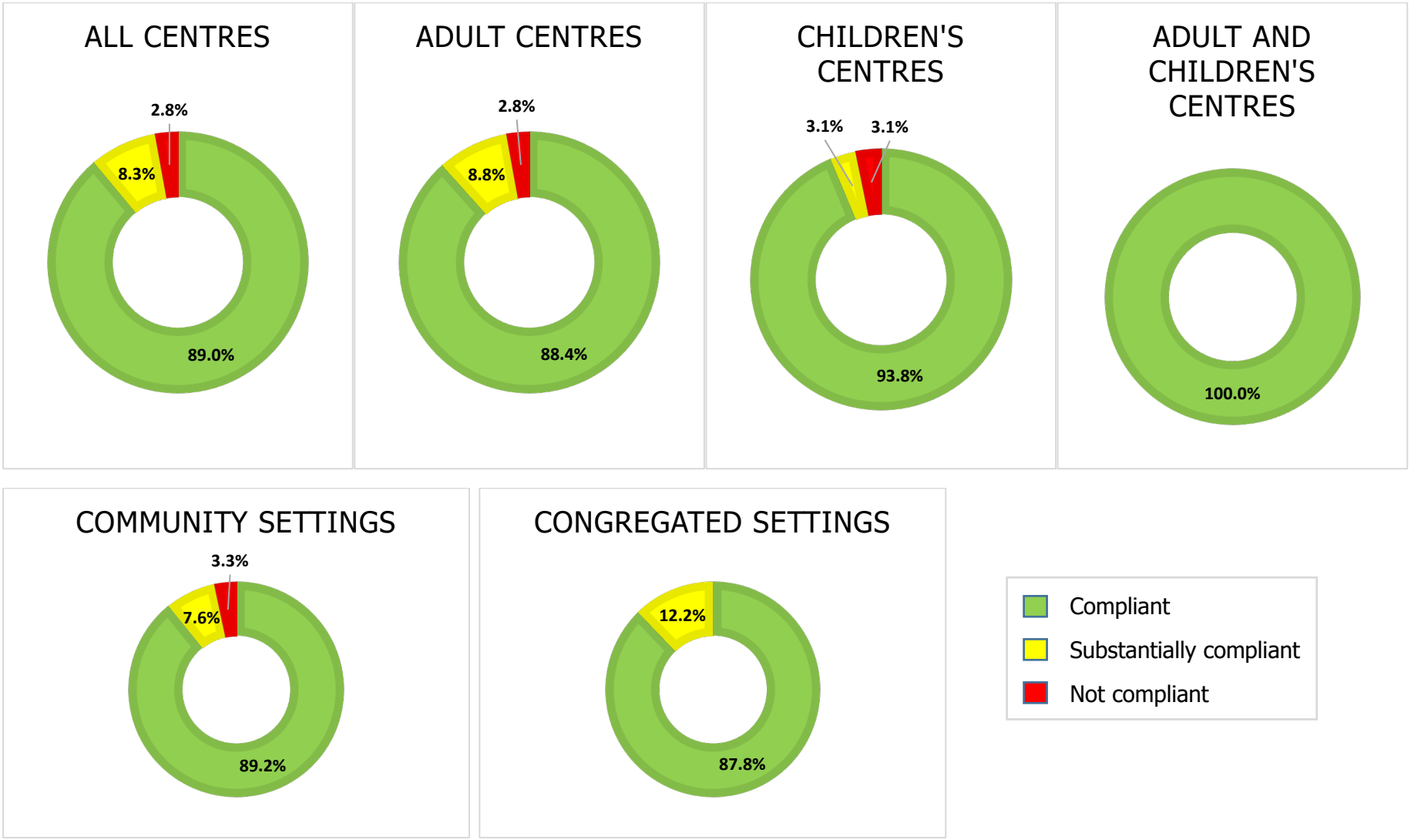



COMMUNITY SETTINGS
10.8%
17.8%
71.5%
CONGREGATED SETTINGS
18.4%
24.7%
56.9%
Compliant
Substantially compliant
Not compliant

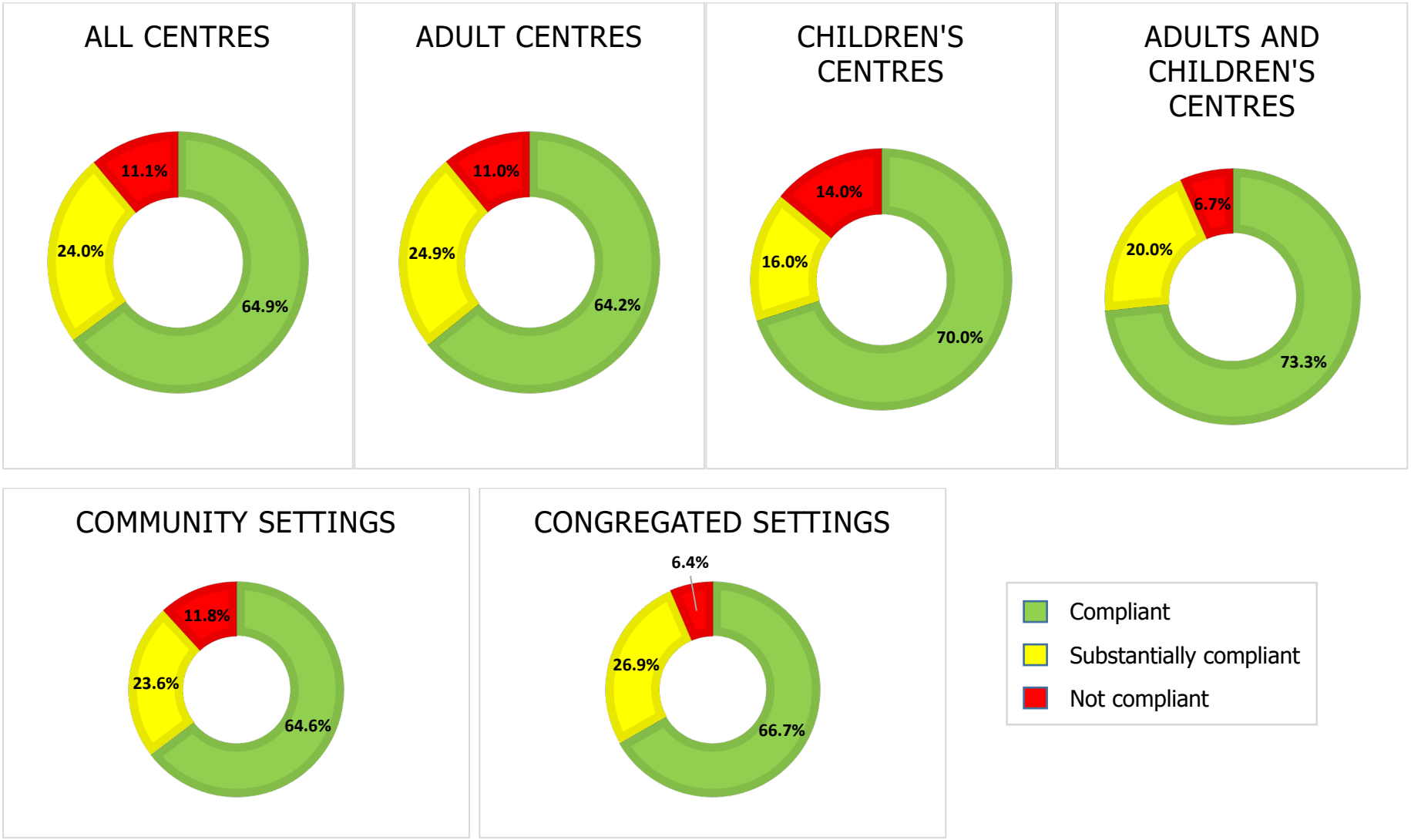
Regulation 5: Individual assessment and personal plan



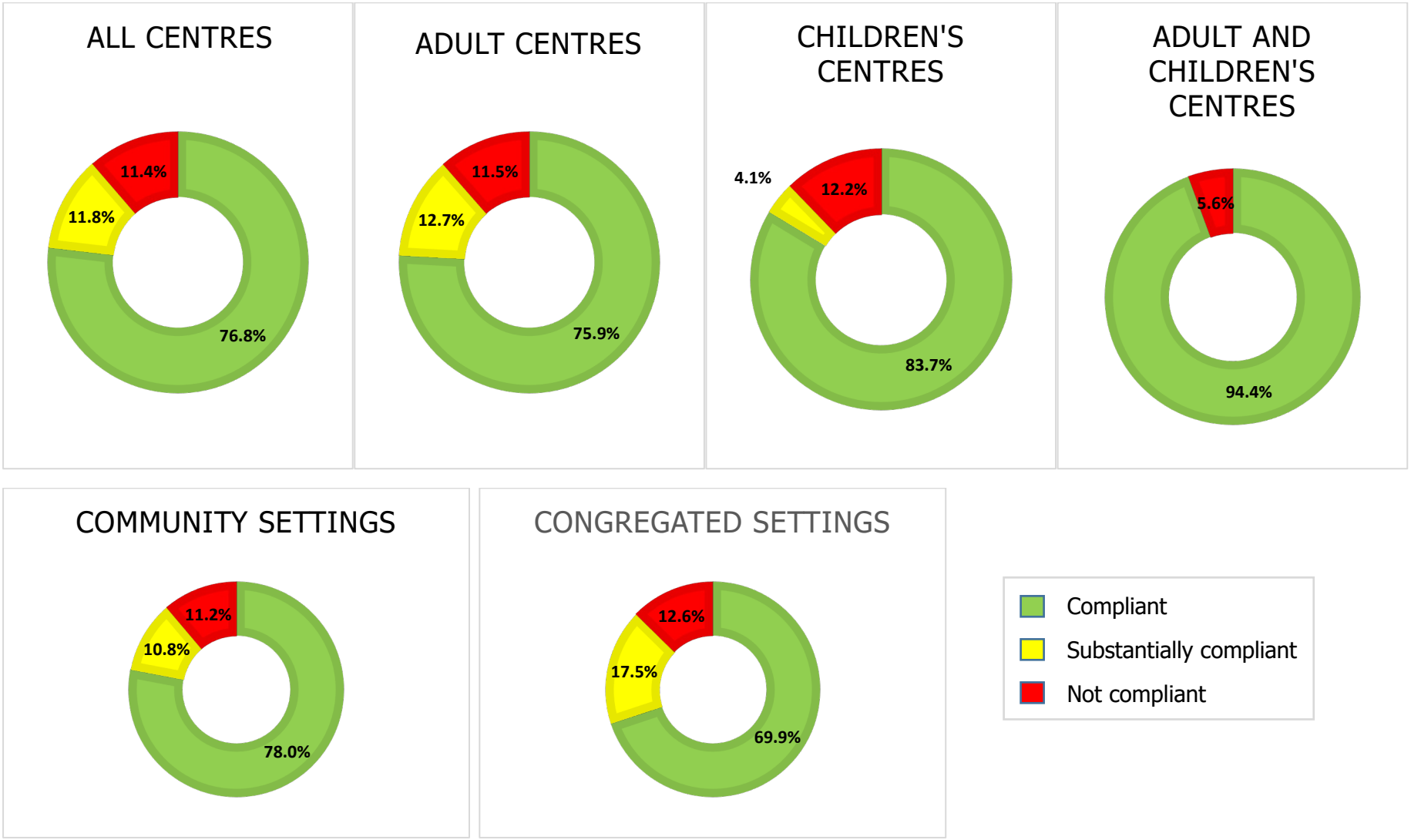
Regulation 6: Healthcare



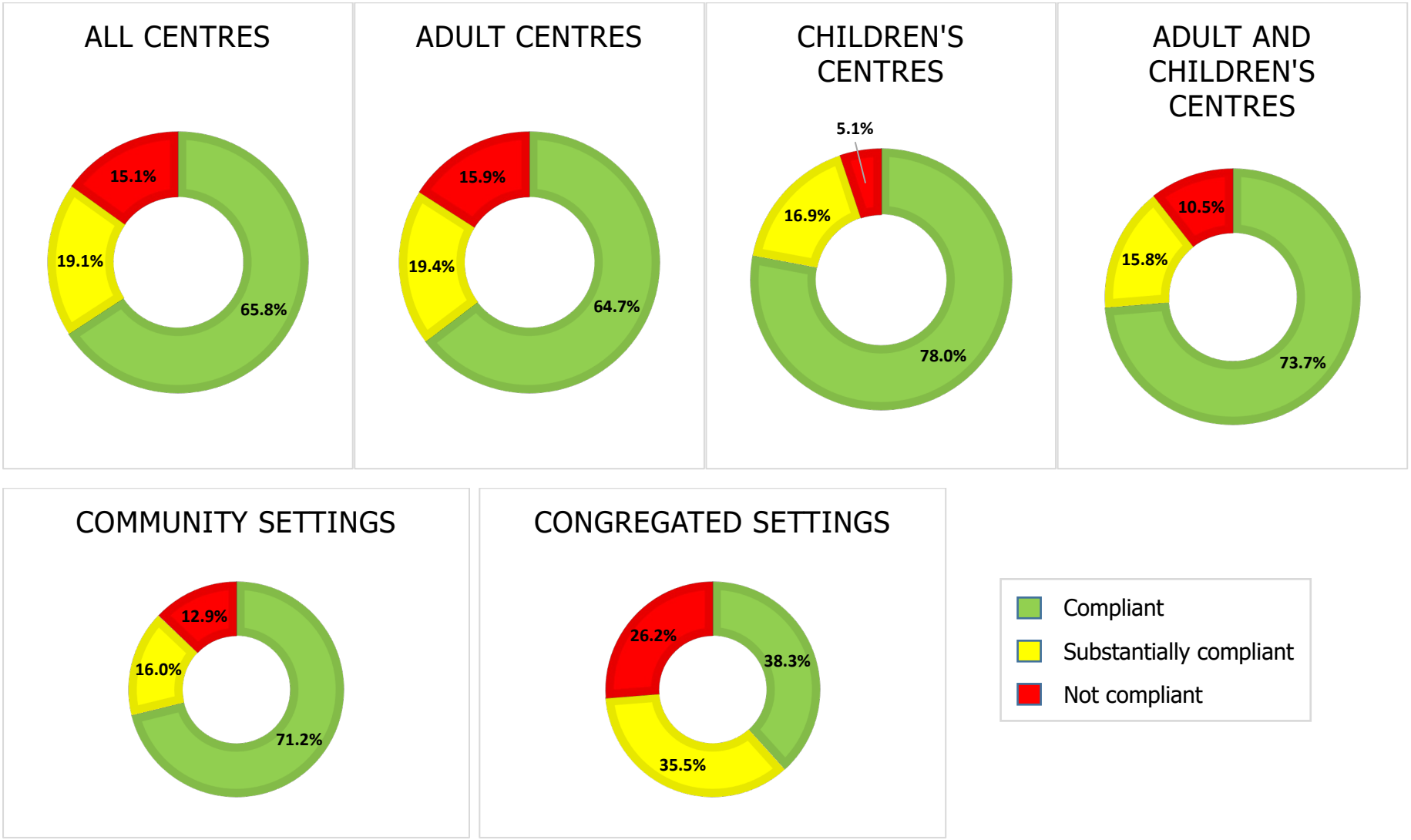
Regulation 7: Positive behavioural support



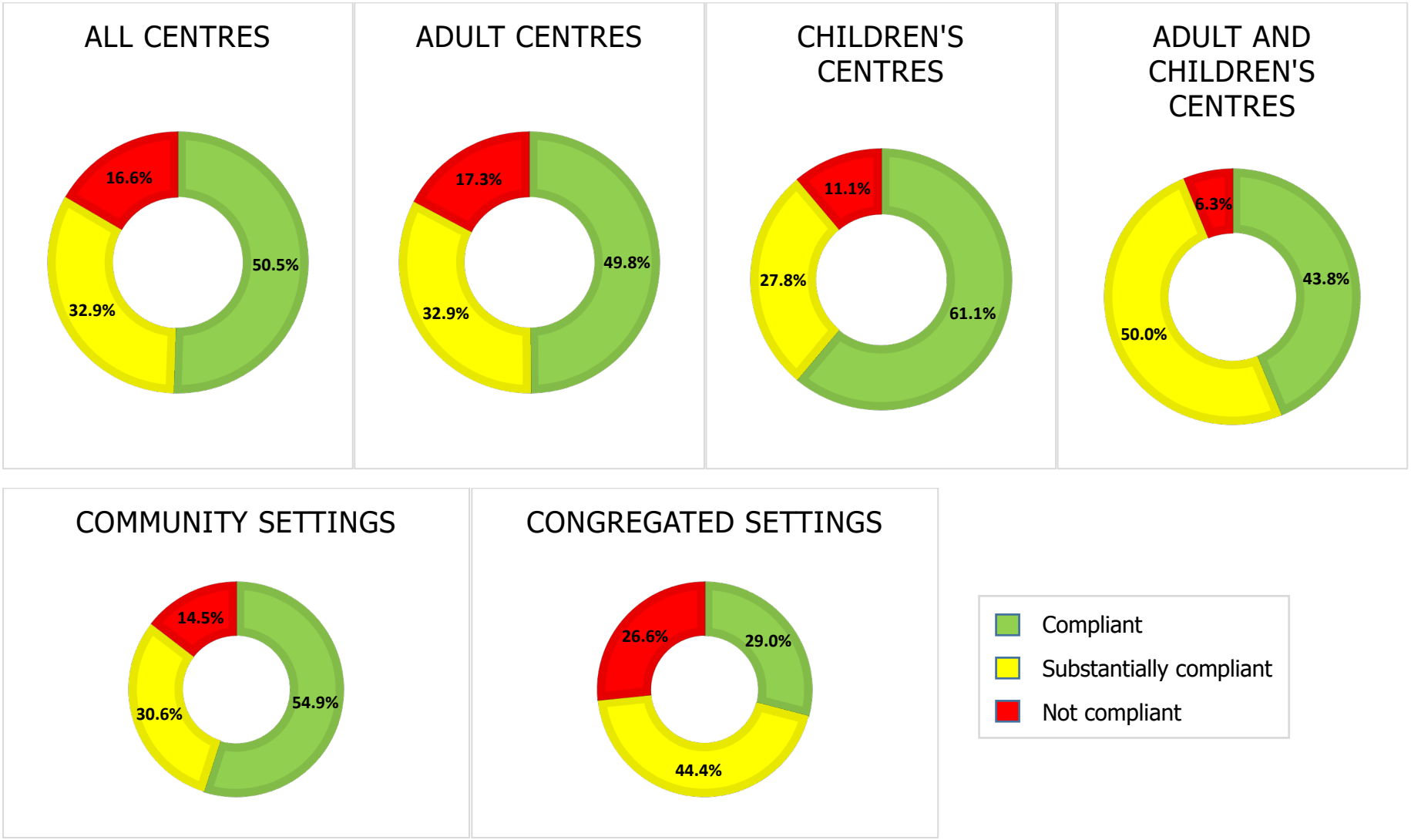
Regulation 8: Protection



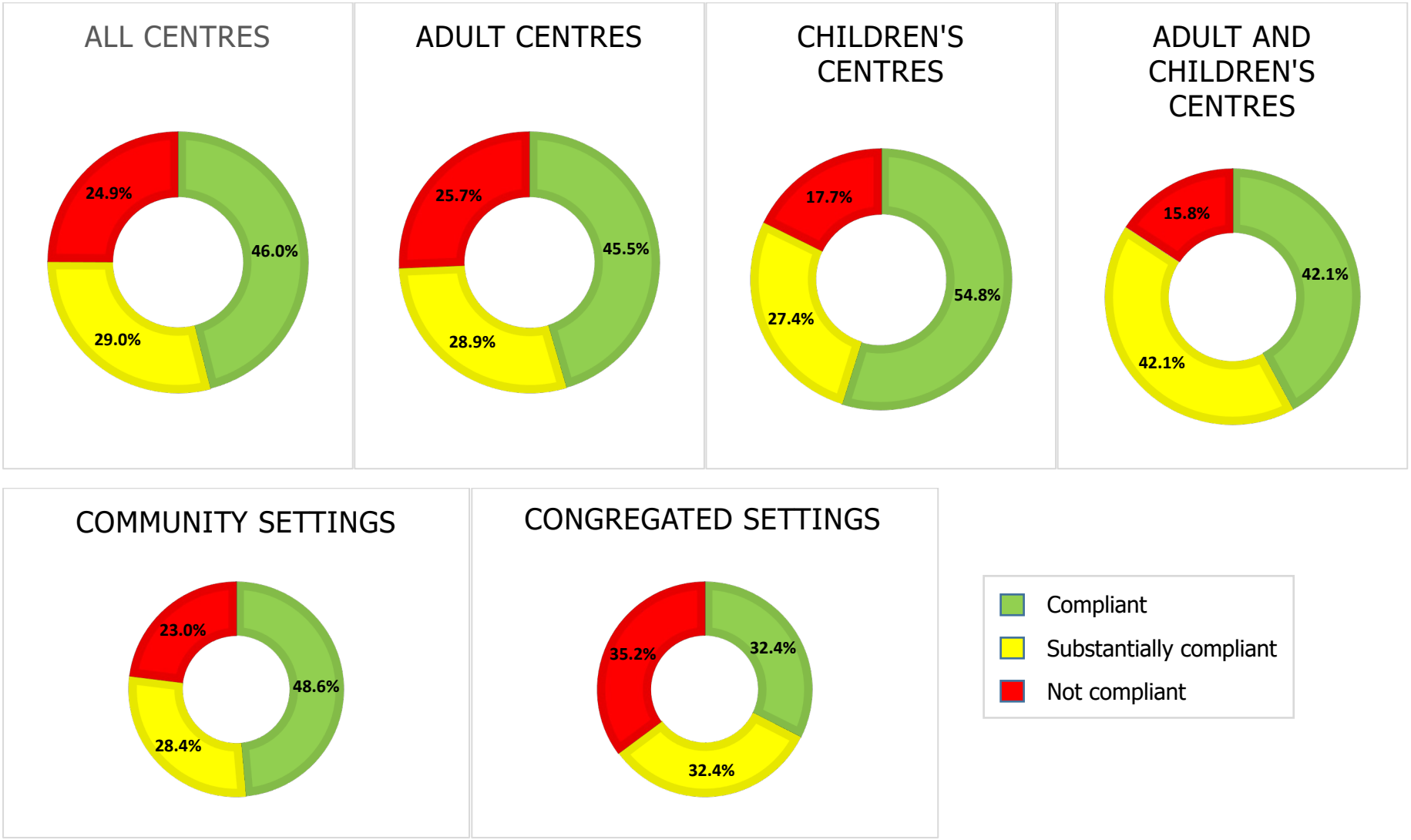
Regulation 15: Staffing



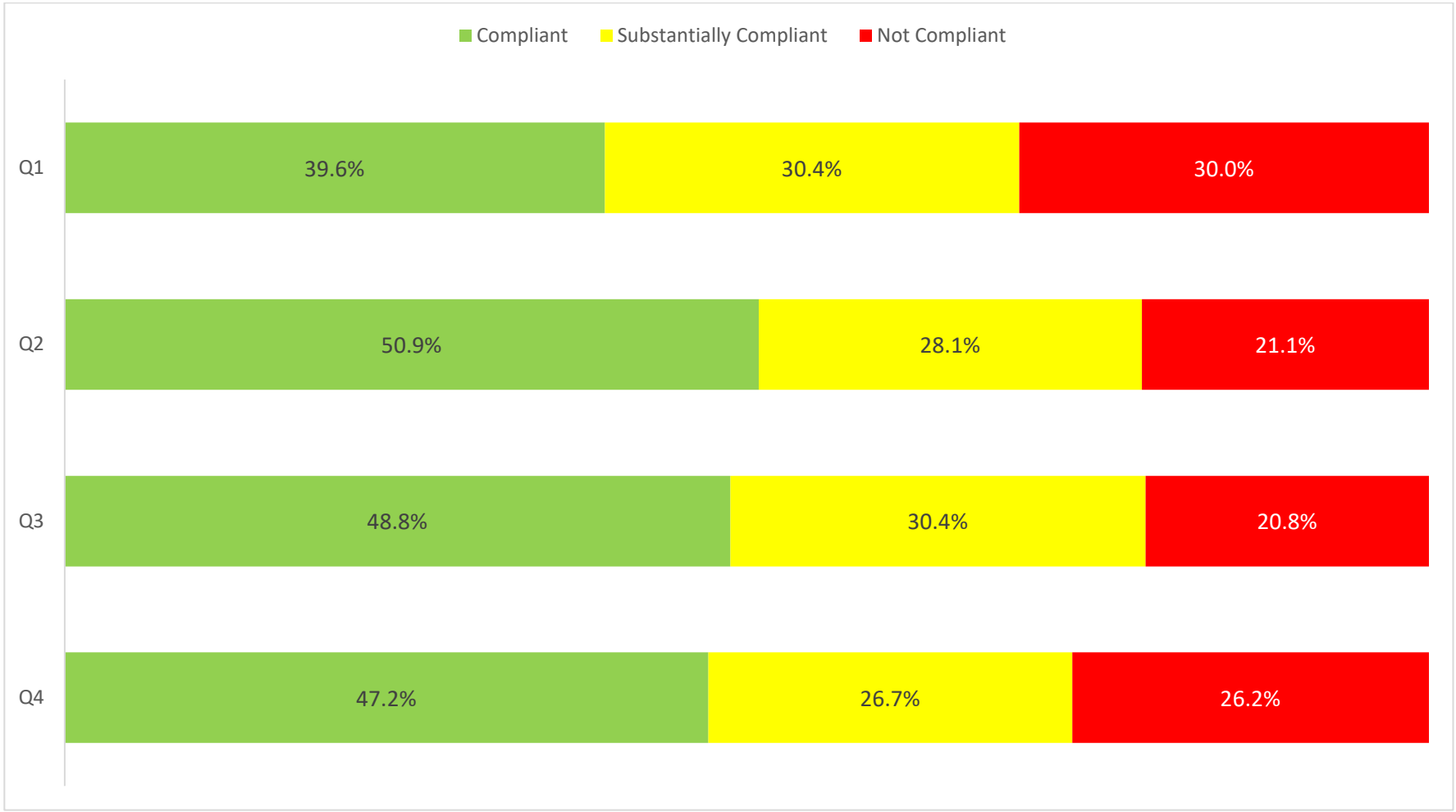
Regulation 17: Premises



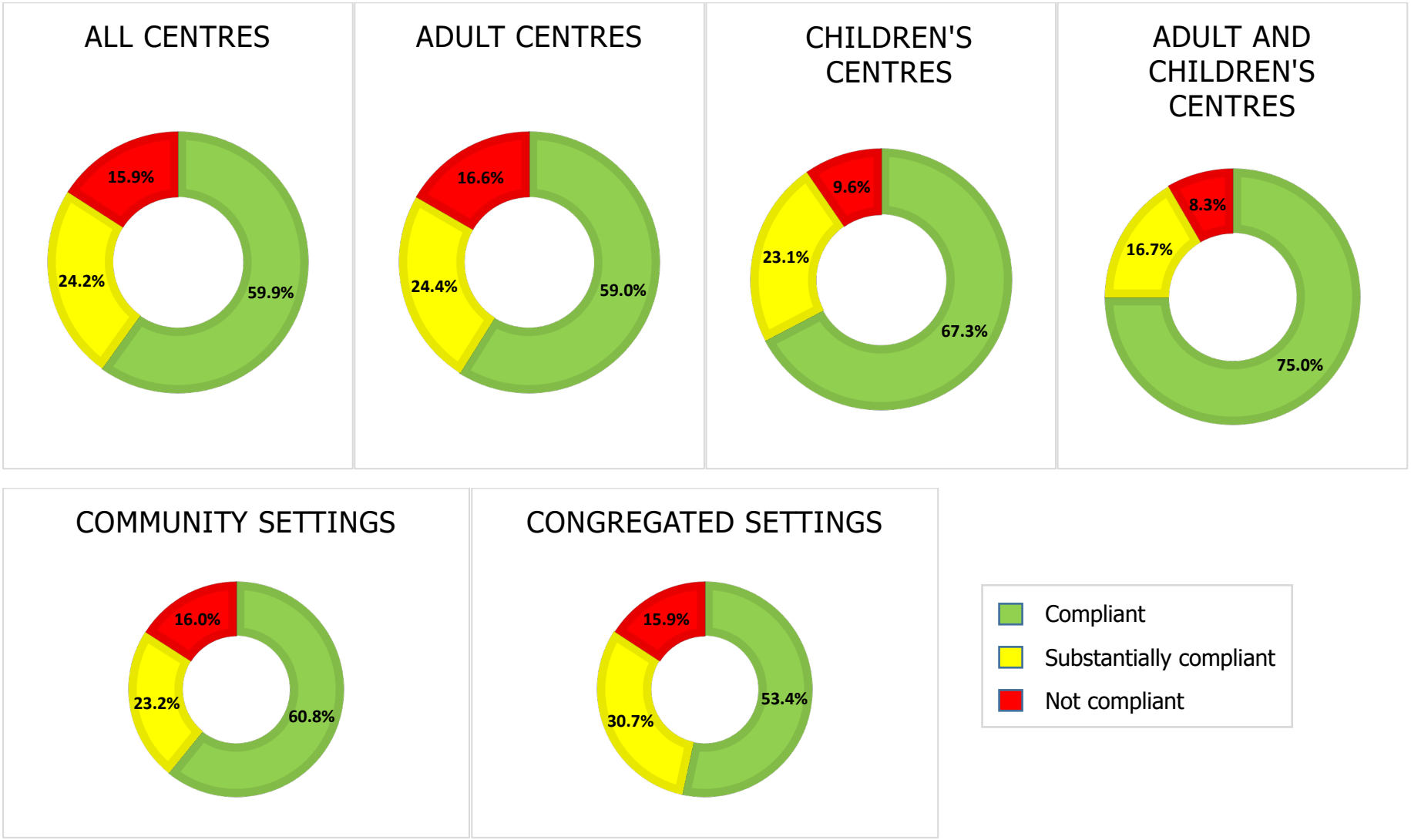
Regulation 23: Governance and management



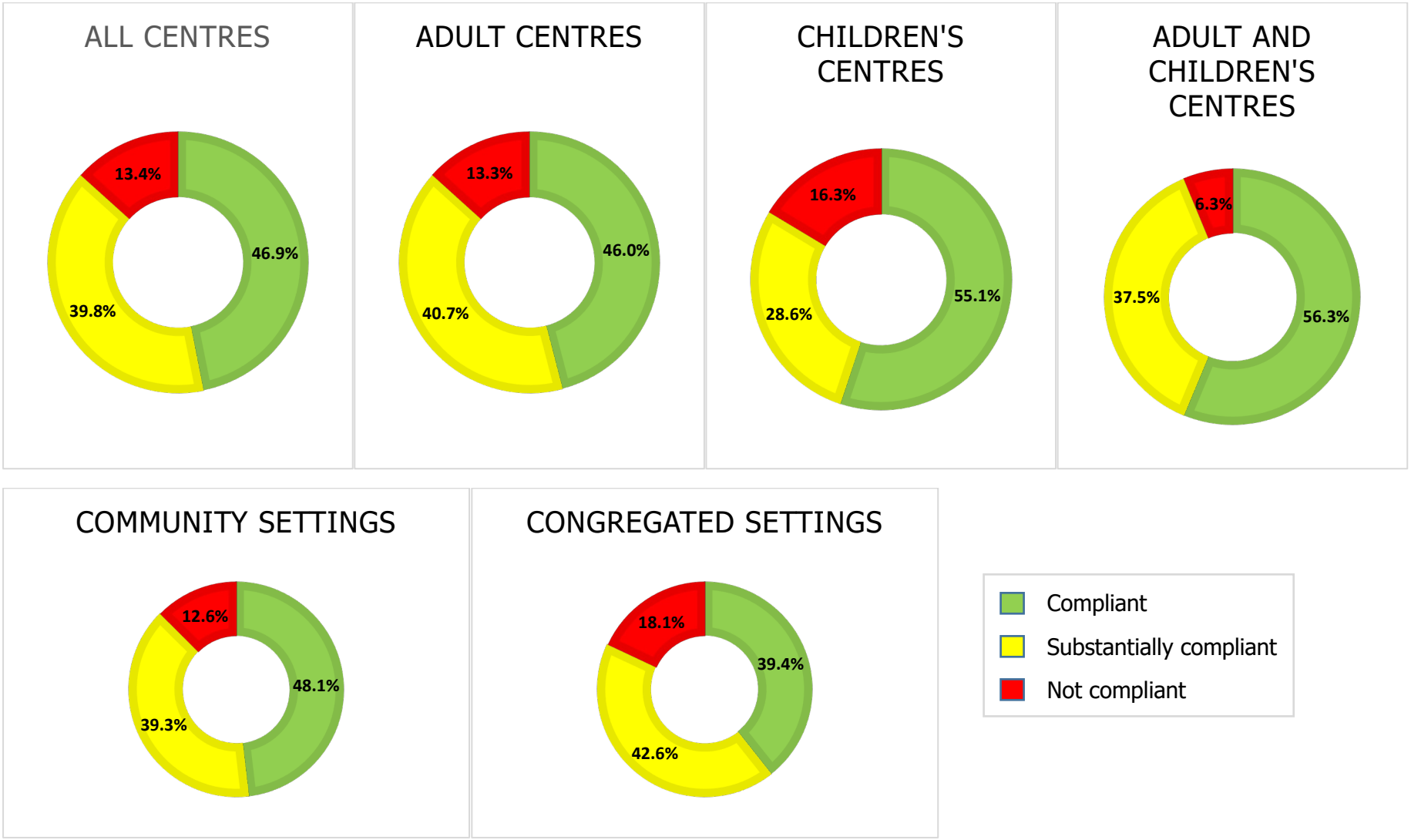
Quarterly breakdown of compliance during 2023 for Regulation 23: Governance and management



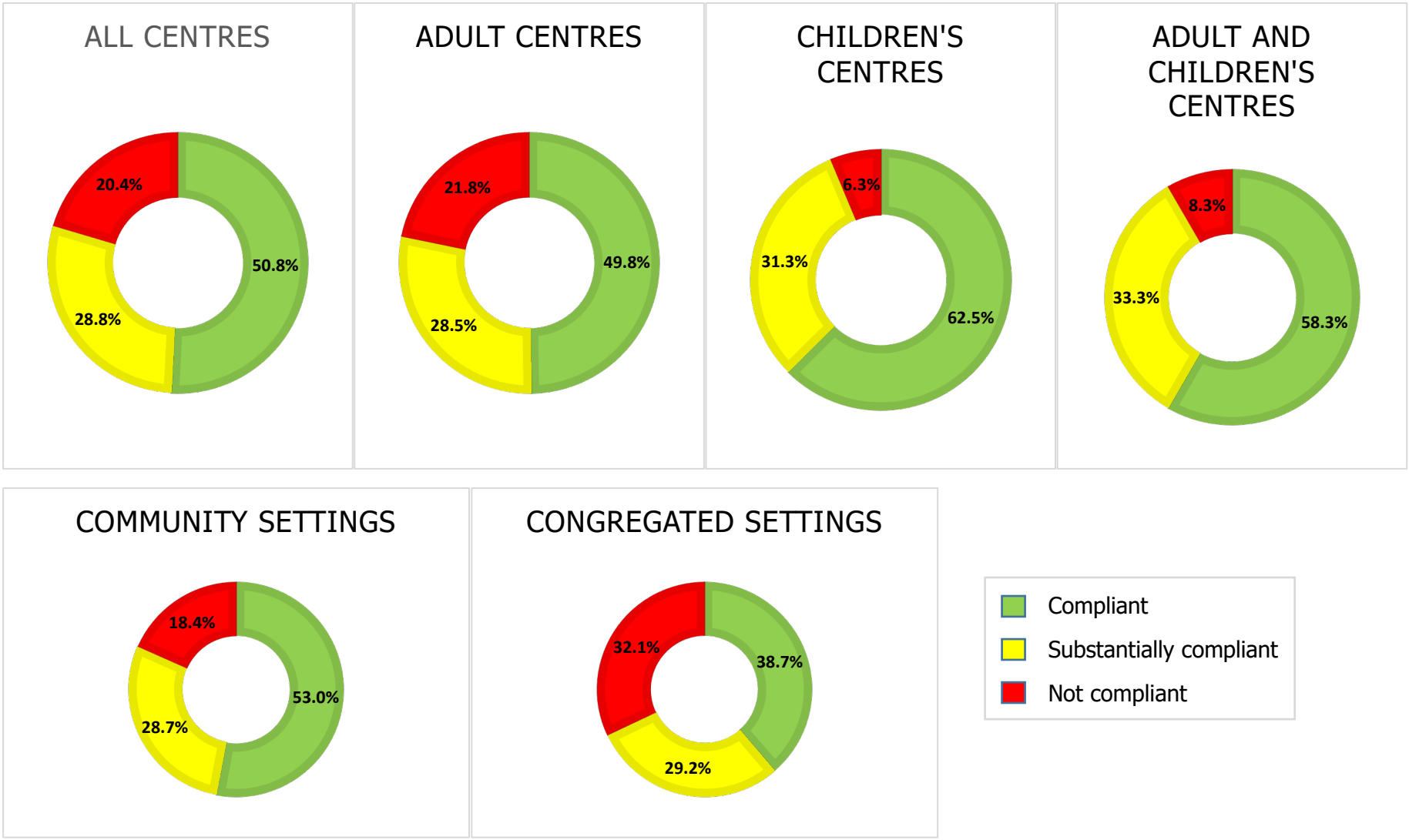
Regulation 26: Risk management procedures



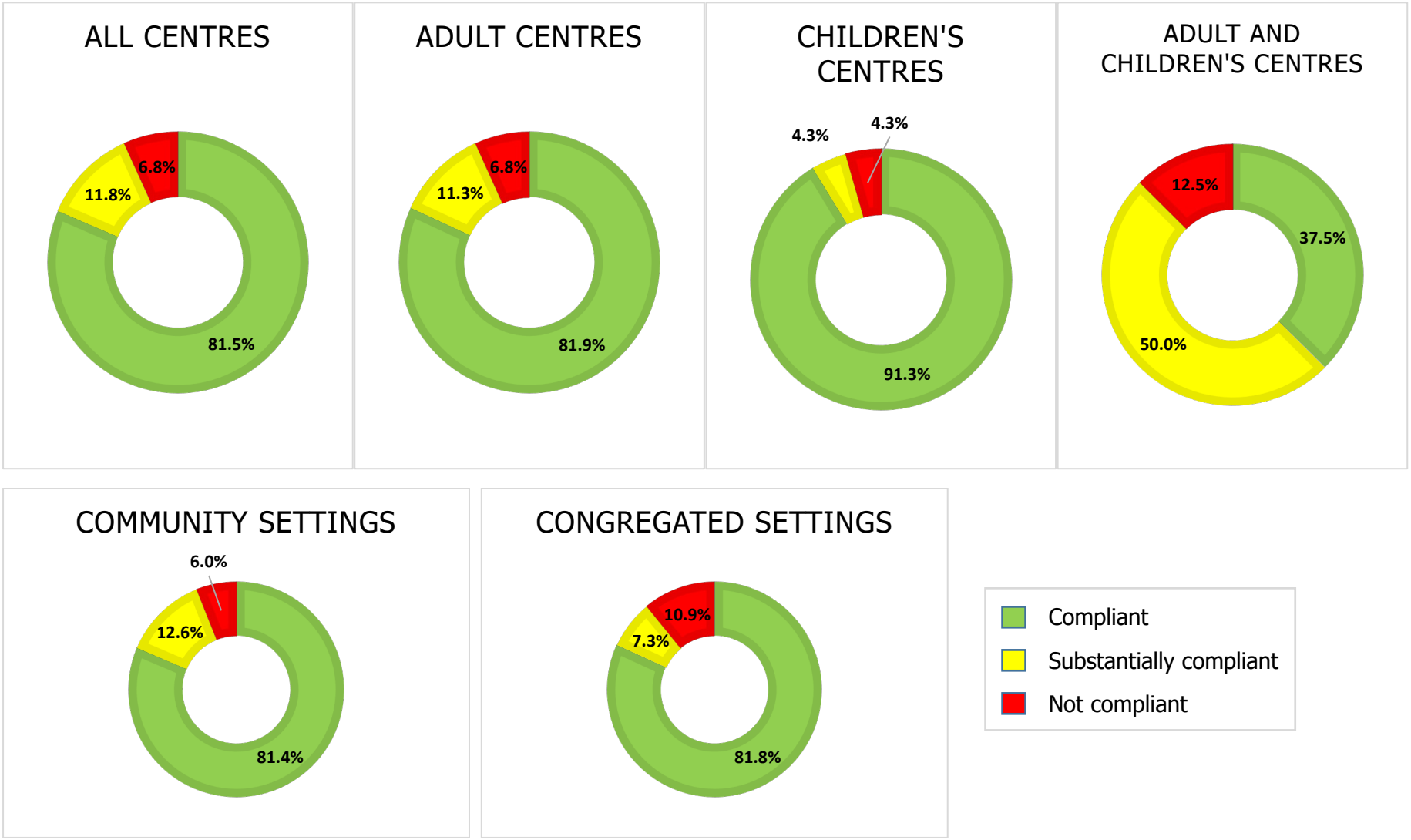
Regulation 27: Protection against infection



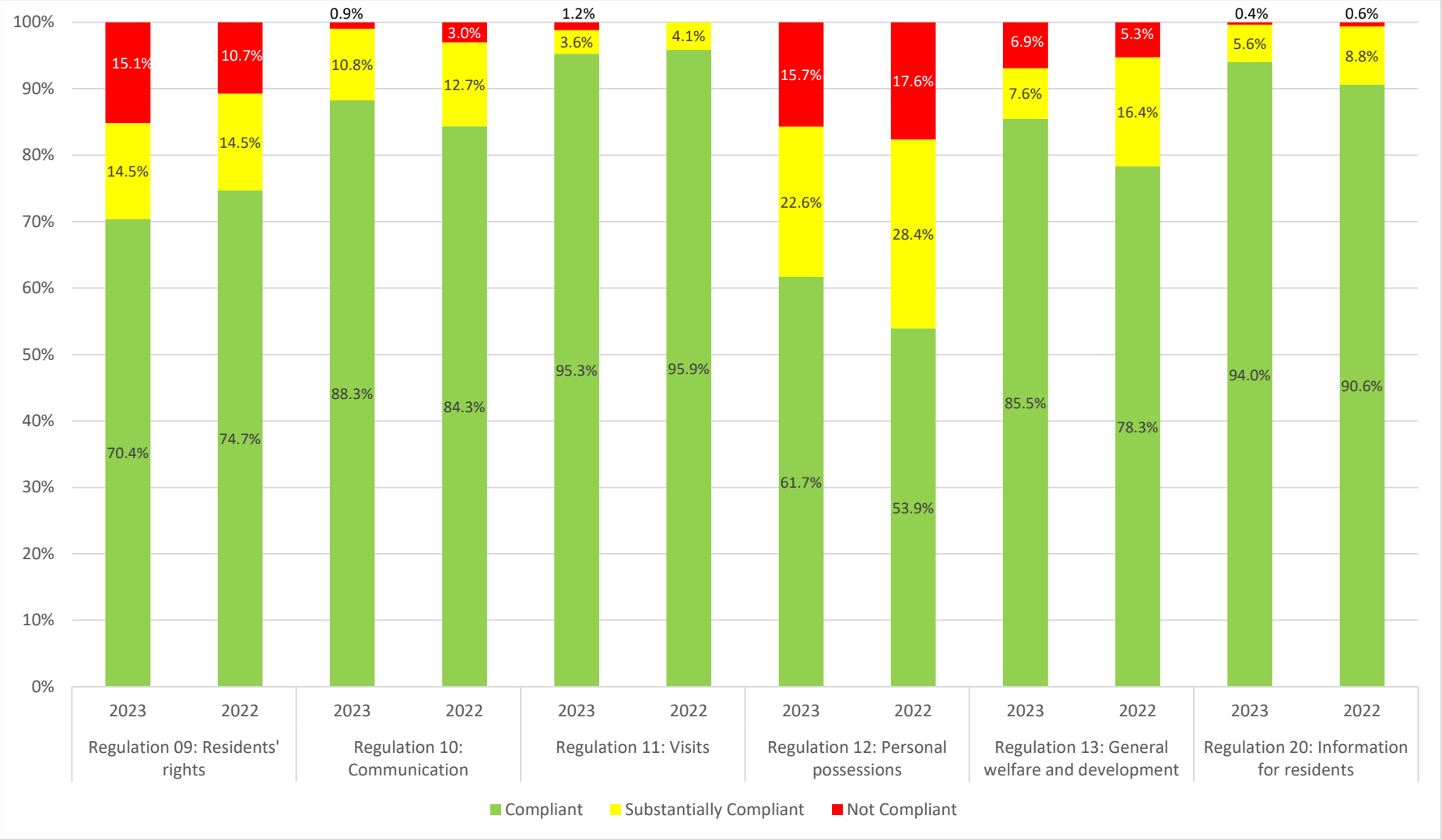
Regulation 28: Fire precautions



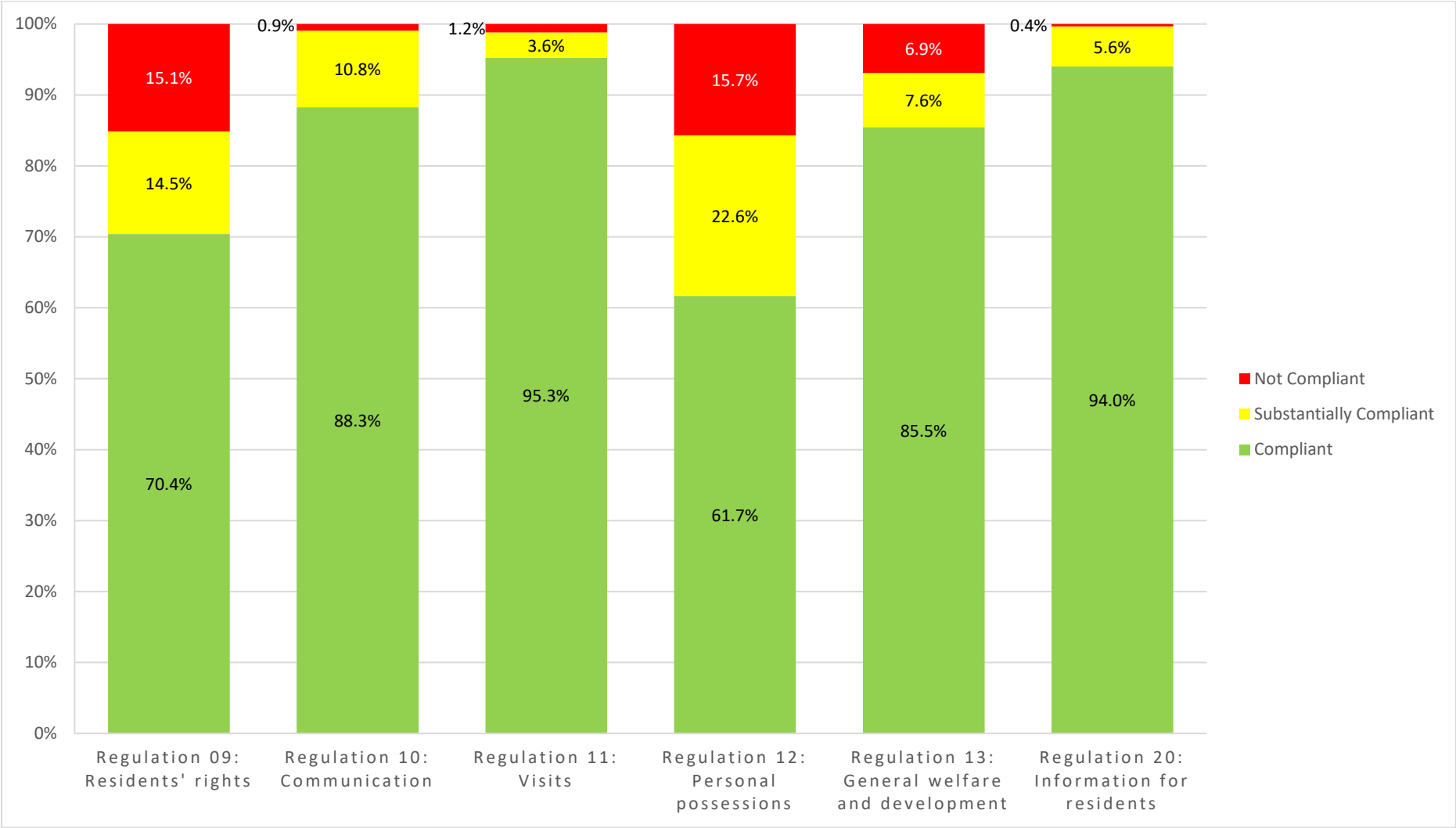
Regulation 34: Complaints procedure



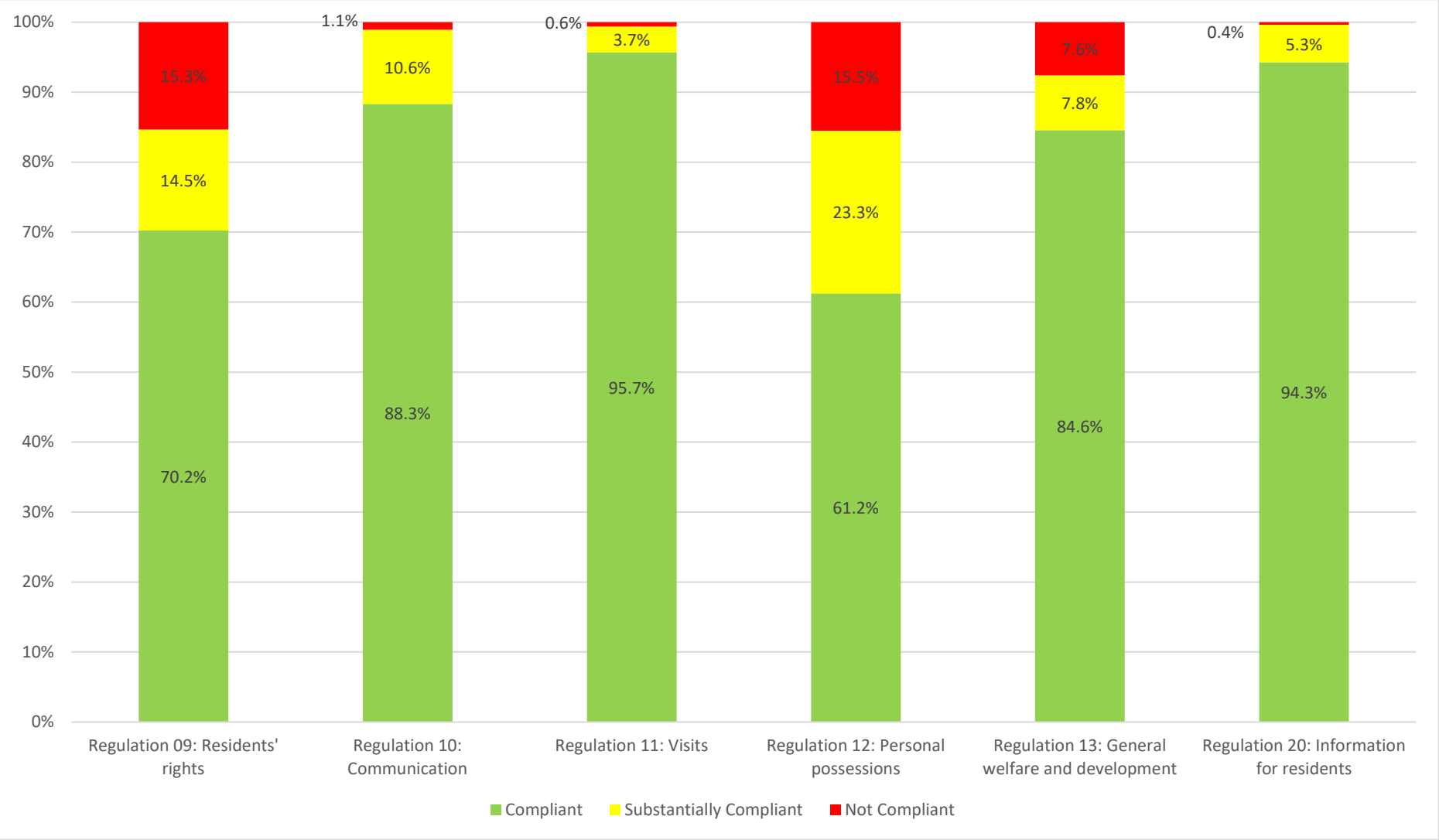
Overview of key rights-based regulations - comparison between 2022 and 2023



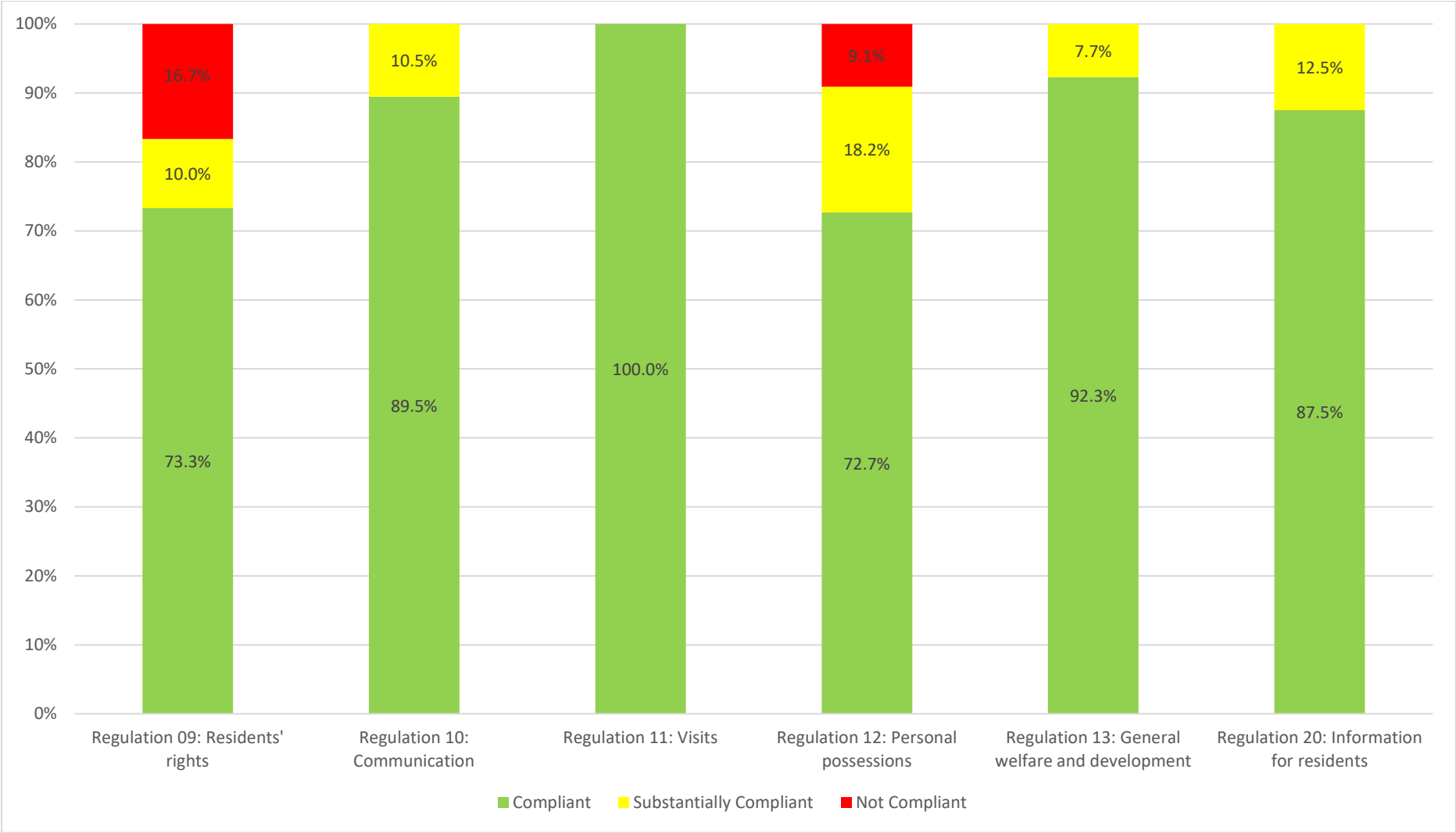
Overview of key rights-based regulations in all centres - 2023



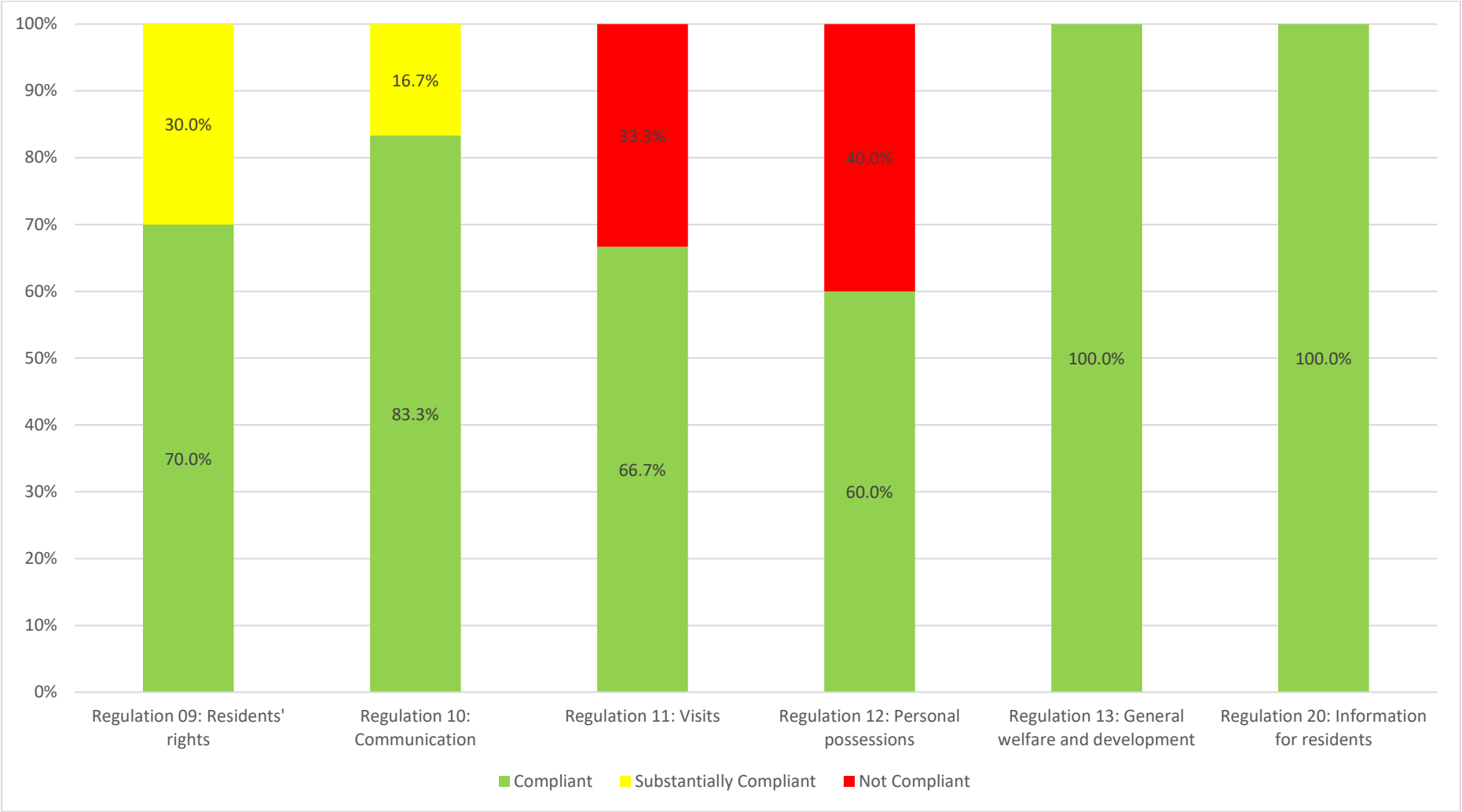
Overview of key rights-based regulations in adult centres - 2023



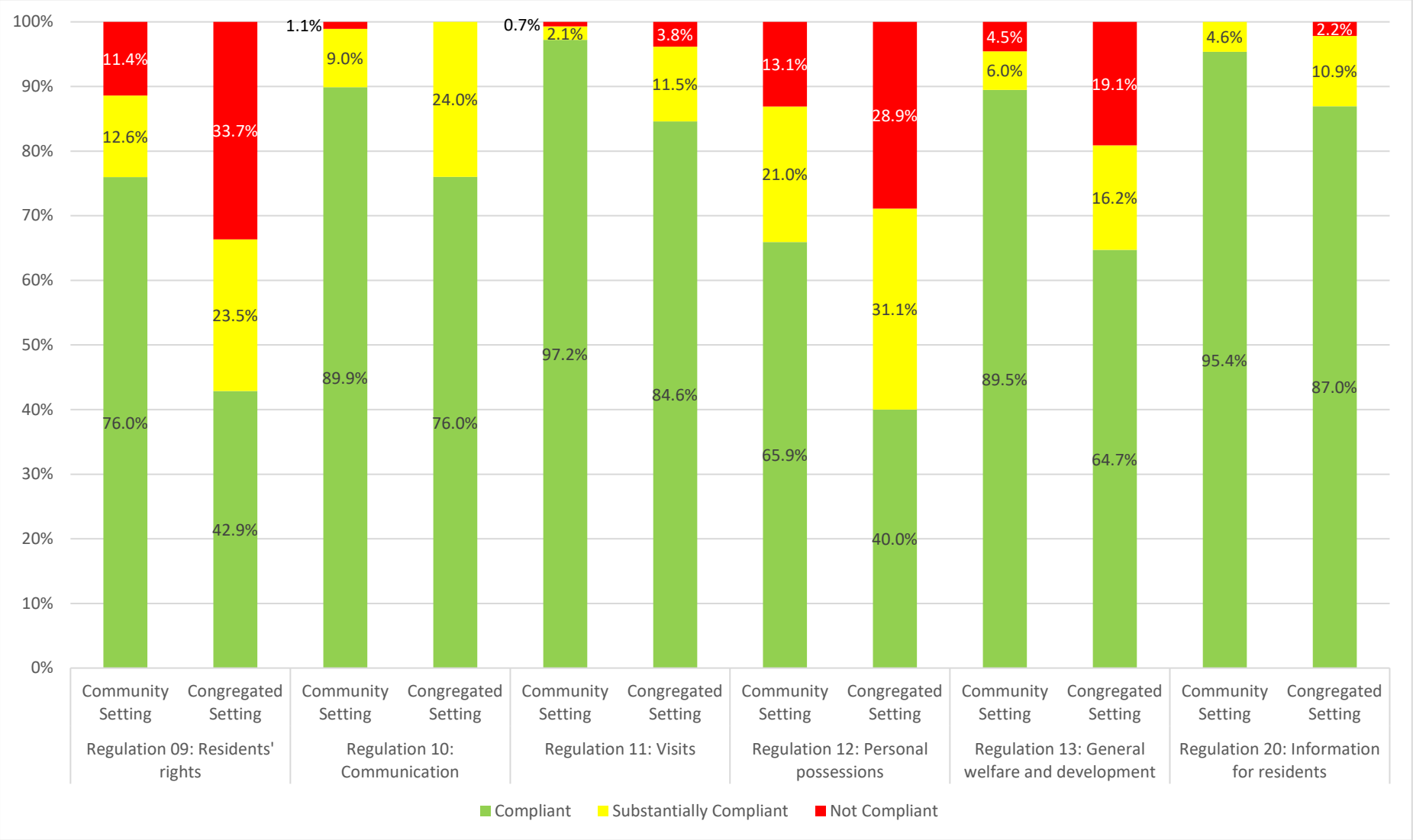
Overview of key rights-based regulations in children's centres - 2023



Overview of key rights-based regulations in centres for adults and children - 2023



Comparison of rights-based regulations in congregated and community settings - 2023



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