

RESIDENT FORUMS

IN CENTRES FOR PEOPLE WITH DISABILITIES IN 2024



Safer Better Care

About the Health Information and Quality Authority (HIQA)

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 relevant government Ministers and departments, 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 serviceuser experience surveys across a range of health and social care services, with the Department of Health and the HSE.

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Message from the Interim Deputy Chief Inspector

Feedback from people with disabilities living in designated centres is one of the most crucial sources of information for the Health Information and Quality Authority (HIQA), informing and guiding our work. A key part of our inspections involves spending time with residents, listening to their experiences, and observing their daily lives.

We would like to extend our heartfelt thanks to all 103 residents across the 13 different service providers for taking part in our Resident Forums in 2024. Your participation and feedback are invaluable to us, and provides us with an essential way to hear your views outside of the inspection process.

Our inspection process comes in two parts – firstly, what residents said about their homes and secondly, the formal assessment of the provider's compliance with set regulations such as safeguarding, residents' rights, fire safety measures, the premises of the centre and overall governance. Both parts of the inspection process are equally important. In some cases, while residents may express overall satisfaction with their homes, our inspectors may find further areas for improvement. All of our inspection reports begin with a section titled "What residents told us and what inspectors observed". Listening to residents and hearing their first-hand experience is really important and the use of resident forums helps HIQA to further understand how we, as a regulator, can do better.

Our inspectors always endeavour to meet residents where possible and hear their feedback about their homes directly. Some residents prefer not to speak with our inspectors during the visit but may decide later to share feedback directly with HIQA or through friends and family. The focus of these resident forums is to listen to residents' feedback and ensure HIQA continuously improves regulation of health and social care services.

All of the feedback from residents in the 2024 forums was really valuable and insightful. Across four different areas for discussion, many residents said that they wanted to show inspectors around their home themselves, that more time should be spent talking with residents and that reports should be in easy-to-read or alternative formats. A key insight was that some residents do not have access to HIQA's written inspection reports about their homes. Many residents expressed a desire for more involvement in decisions that affect them and said that they really value independence and community involvement in their lives.

As a result of these forums with residents, in our forthcoming inspections, HIQA will endeavour to spend more time with residents and involve them more during inspections, seek residents' permission to ensure their privacy is always upheld and to create easy-to-understand tools, using simple language and different formats.

I would once again like to thank the residents who took part and shared their views with us, the staff members and advocates who supported them, and the service providers who facilitated the forums.

We look forward to continuing these valuable forums in 2025.

Ciara McShane

OflShane

Interim Deputy Chief Inspector of Social Services (Disability)



What residents told us:









1. Introduction

This report details the views and experiences of people living in residential services for people with disabilities in Ireland (known as designated centres), gathered through a series of forums (meetings) with residents.

While the Health Information and Quality Authority (HIQA) regularly meets with residents during inspections, these forums provide an opportunity for residents to share their views outside of the inspection process.

In 2024, we held 13 face-to-face forums across the country, with 103 residents participating from centres operated by 13 different service providers. We would like to sincerely thank all of the residents who took part and shared their valuable feedback, which has informed our work and will help us to improve our approach going forward.





2. How we gathered residents' views

HIQA contacted a selection of providers in various regions across the country. We asked them to select a number of residents using their services to participate in these forums. The providers, residents and resident-led advocacy groups decided among themselves who would attend, with an aim to have a good representation of the residents living in the provider's centres.

Before the forums, we sent information to participating residents. This included accessible consent forms, information leaflets, and 'nice to meet you' documents to introduce residents to the HIQA people who would be attending the forum.

The agenda was set to ensure consistency across meetings, while also allowing time for open discussion and to give residents the chance to ask questions and share their views in their own way. At least two HIQA representatives attended each session, taking notes as residents shared their views on four key areas:



The next section of this report presents the feedback shared by residents on each of these areas.

¹ HIQA developed easy-to-read 'nice to meet you' documents following feedback received in resident forum meetings held in 2021.







3. What residents told us

3.1 What does HIQA do and what is an inspection?

During the forums, residents shared their thoughts about what HIQA does and HIQA's inspections in their homes. The key themes which emerged from the forums included that residents wanted more involvement and interaction during the inspection process.

Residents told us they felt HIQA's role was to support them and check they were safe, to listen to their views, and to ensure the designated centre was up to standard.

"To make sure everything is working properly and that the person supported is ok and has a safe environment."

Residents said they felt inspections were important and that inspections had led to improvements in their homes. For example, one person told us they got a bigger bedroom following an inspection, while another person shared how the centre's office was moved from the sitting room, meaning they could watch TV undisturbed. This also ensured their privacy was respected. Residents felt inspections allowed them to hear about what a good job the centre was doing, and were a good opportunity for staff to get advice on how to do things better.

"It's all about us, isn't?"

Residents spoke about the importance of being included in conversations about their lives and homes. They spoke about how HIQA ensures they were more involved in decision-making and to have choices in their lives. One resident shared how HIQA ensured they were involved in planning their move to another centre through a transition arrangement, as well as choosing the paint colours when their house was redecorated.

"I really like showing the HIQA inspector about my home and chatting to them about things I like to do."

"I am happy to chat to the inspector. They come to have a nosy around."

Most residents were positive about the inspection process, especially when inspectors took the time to sit and chat with them. They explained that they would prefer inspections to be relaxed and not too formal. They enjoy showing inspectors their bedrooms and talking about their daily lives, and felt inspectors should spend more time with them. Residents felt there should be more interaction between them and the inspectors, even if that meant the inspector was just sitting in the same room as the resident while reviewing documents.

"It should be 50:50 - the residents and staff speaking with inspectors."

Some residents stated that, if they are out for the day when an inspection occurs, centre staff should let them know so they can come back and meet the inspector if they want to. Some residents preferred meeting inspectors individually, while others preferred a group setting. This also highlighted that these preferences can change from one inspection to the next. A few residents expressed feeling nervous about inspections, and it was noted that residents availing of respite services felt less familiar with HIQA and the inspection process.

"When you hear they are coming, you would be nervous."

"I get stressed over the HIQA visits."

Some residents said they prefer announced inspections, as they like to know when the inspector is coming, so that their freedom and privacy are respected. Others spoke about the importance of unannounced inspections to find out if there is a problem or not. Residents also had views on inspection times. Some liked to meet inspectors in the morning, while others preferred afternoons or evenings, after day service.

"I don't like when I don't know that HIQA are calling."

"You need to make sure you are not interrupting our freedom or privacy."

Residents spoke of the importance of respecting their privacy. Although most residents liked showing their bedrooms to the inspectors, one shared they did not. All residents agreed they felt inspectors should ask first before going into their bedroom and not look if they are not at home. They also said they should be with the inspector when they are looking at their paperwork, especially their personal plans.

"I don't like anyone in my room."

"It's my private space."

"Your home is your castle and your bedroom is your palace."

Key feedback from residents on HIQA and the inspection process

- Residents understand HIQA checks that their homes are safe and improves their living conditions.
- Residents want to show inspectors around their home themselves, rather than staff.
- Residents prefer to know when inspectors are coming and who the inspectors are.

- Residents want inspectors to spend more time speaking with residents and less time on paperwork.
- Inspectors should always ask permission before entering bedrooms, especially if residents are out.
- Some residents would like to visit the HIQA offices to better understand its role.
- Information to explain inspections would improve people's understanding.

Resident Forums in Centres for People with Disabilities Health Information and Quality Authority







3.2 What happens after an inspection?

The residents told us about their experiences of what happens after inspections. The key themes expressed by residents were a desire for access to inspection reports and involvement in discussions after inspections in their centres.

Some of the residents said they had access to the inspection reports, either at their home or were given a copy, and that these reports were discussed with them.

"It would be discussed with us at a house meeting."

However, a large number of residents said that they did not readily have access to inspection reports. They agreed it was important to see the inspection report to find out what they say about their homes and wanted the reports shared with them.

"Unless we ask, we're not told."

"Never see the report - too private."

However, some residents said they did not understand the report and said that it would be important to them to make more easy-to-read or alternative formats available, especially for those residents who have sight or hearing impairments. Residents liked that the reports were published on the HIQA website, but one resident said they would like to be consulted about whether the report should be published. Some residents discussed how the reports of their home might be in the local newspapers.

"I would like an easy-to-read report from HIQA."

Residents reported they did not know what happened after an inspection and said they wanted to be more involved in discussions about the inspection results. Some residents expressed an interest in learning the outcome of the feedback meeting between inspectors and the provider after the inspection is completed. It was suggested that the provider hold a separate session for them.

Key feedback on what happens after an inspection

- Some residents have access to inspection reports, but some do not.
- Reports should be in easy-to-read or alternative formats.
- Residents would like to know more about the post-inspection feedback.
- Staff should read or explain relevant sections during their house meetings to support access.

Resident Forums in Centres for People with Disabilities Health Information and Quality Authority







3.3 Residents' rights

"I have a right to be safe and happy."

Residents across the country showed a strong awareness of their rights and gave examples of how these are respected in their daily lives. They talked about being able to see family, lock their door, manage their own money and live in a safe and comfortable home. Many said they felt respected and mentioned having their own bank card. They talked about the importance of staff knocking before entering their rooms and having privacy when visitors come over. Some residents also felt staff should be reminded to always knock before entering their rooms.

"Dignity and respect are key."

Some residents also spoke about challenges with their rights. A few residents said their bank cards were kept in a safe by staff, meaning they had to ask to access their own money. Others said they could not always go out because of staff shortages or felt they did not have enough say in decisions, like going shopping or what to buy.

Residents spoke a lot about choice and independence. They described deciding where they went, what they ate and how important it was to be part of the community. One resident said they loved having a quiet home and would go for a walk if it got too noisy. Others spoke about how much their independence meant to them and how they had been supported to take part in education and work.

Many residents said they had regular meetings in their homes where they discussed things like food choices and activities. Another said their house did not have meetings. Some also felt that when they did speak up, their views were not always listened to.

Some residents shared experiences where they felt their rights of choice and decision-making were limited. Two residents mentioned a concert which they wished to attend but was cancelled at the last minute without explanation. They felt it was due to concerns about another resident potentially having a "wobble" at the event, which meant no one was able to go. Another resident said their doctor decided what food they could eat because of their weight and staff would not let them have a takeaway if they wanted one. Another resident shared how they did not get a say when they moved house.

"They found us a house but never asked us if we wanted to live there."

Residents talked about getting out and about, saying they went on trips with staff, volunteered or had jobs.

The residents showed a good understanding of their rights. Some said information about their rights was displayed in their homes or included in easy-to-read booklets. Residents spoke about their right to privacy and to make their own choices.

"I have a right to speak up for myself - that is the right thing to do."

"I am supported to be healthy. I have the right to decline my bloods being taken and other medical interventions."

Overall, residents felt their rights were respected in many ways, but also saw areas where things could improve. This was particularly around communication, decision-making and ensuring their privacy and independence are always upheld.

Key feedback on residents' rights

- Residents showed strong awareness of their rights and emphasised the importance of having them respected.
- Residents expressed a desire for more involvement in decisions that affect them.
- While many residents feel their rights are respected, they feel there is room for improvement in areas such as privacy, independence and decisionmaking.







3.4 Residents' agenda items

Residents had an opportunity to share their own agenda items and topics that are important to them in their daily lives. They spoke about how they spend their time, discussing activities such as bowling, swimming, going to the cinema, using computers, attending day services and volunteering. Others spoke about playing snooker, watching football, enjoying music or taking part in art, first aid and choir. One resident talked about planning their birthday and the upcoming Christmas party. Another resident read two poems they had written, one of which was about HIQA.

Residents discussed their living arrangements, highlighting the importance of having their own bedroom and personal space. Some spoke about noise levels in shared living environments or expressed their desire to live separately from others. The challenge of sourcing suitable housing was mentioned, along with the impact of waiting for their "forever home."

The importance of community involvement was a recurring theme. Residents spoke about feeling part of their local area and wanting safe and welcoming communities. One resident, a member of an advocacy group, spoke about their work lobbying for safer road crossings and developing easy-to-read documents.

"I know that I have the right to be part of my community."

Residents reflected on their independence and autonomy. They spoke about courses they had completed or enrolled in, such as money management and computer skills. Others highlighted the importance of having access to their own phone and transport options to support their daily activities.

The residents spoke about the importance of having the right staff. They also highlighted the need for familiar and consistent staff. Many residents said that they felt supported by staff. One resident spoke about their key worker helping them to save for bigger purchases. Another spoke about how staff supported them to move to a new home.

"If we didn't have good staff like we do, warm and caring staff, then we wouldn't be safe in our houses."

"It's the staff make the house a home."

"I like when staff I know really well support me."

"We go home holding our breath, not knowing who will be there or what they will decide for me."

Residents shared personal achievements and experiences:

"I got the train to Galway this year. It was my first time for a few years since I used the train and I am very proud of myself."

"I went on a mini cruise to France and spent two nights on the ship and I was not afraid. I am planning another trip for next year."

"I have lots of medals and pictures of my achievements."

"I love dogs and puppies, and I like volunteering with the animal foundation."

Residents spoke positively about the forum itself. They valued the opportunity to engage with inspectors outside the formal inspection process and in a setting that was not their home. They appreciated having a space to share their views, discuss their rights and provide feedback on their lived experiences.

Other key areas important to residents

- Residents shared key topics, including how they spend their time and the activities they enjoy.
- Residents emphasised the importance of personal space, managing noise and compatibility with housemates.
- Residents highly value independence and community involvement.
- Residents appreciated the forum and the opportunity to engage with HIQA.

Conclusion

The views of residents are very important to HIQA and inform how we do our work. We continue to hear from residents through the inspection process and through the feedback provided through residents' questionnaires, which are issued prior to announced inspections.

During 2024, the resident forum meetings allowed us to meet with residents outside of the formal inspection process, in a setting that they felt comfortable with. These resident forums provided an environment where they could speak openly, share their lived experience and offer feedback on the inspection process.

The insights gained from these forums have been invaluable and will play a key role in shaping future inspection activity, particularly in how we conduct inspections with and for residents. This approach aligns with our commitment to a human rights-based approach, ensuring residents' voices remain at the heart of our work.

As a regulator, HIQA will continue to conduct the inspection process in a way that protects residents living in designated centres, upholds their rights and ensures their safety and the standard of care and support which they receive in their homes.

Given the value of these residents' forums, we will continue them into 2025, to ensure we continue to have meaningful engagement with residents and can make improvements in how we do our work.

Following the 2024 resident forums, HIQA will take a number of actions in its work in residential centres for people with disabilities.

Key actions for HIQA

- We will spend more time with residents and involve them more during inspections.
- We will look for more opportunities to engage with residents, outside of the inspection process.
- We will uphold residents' privacy and ensure it is respected during inspections by ensuring we seek permission to enter their bedrooms.
- We will create easy-to-understand tools, using simple language and different formats to ensure residents have access to more information about our work.

Summary of feedback from residents

Key feedback on HIQA and the inspection process

- Residents understand HIQA checks that their homes are safe and improves their living conditions.
- Residents want to show inspectors around their home themselves, rather than staff.
- Residents prefer to know when inspectors are coming and who the inspectors are.
- Residents want inspectors to spend more time speaking with residents and less time on paperwork.
- Inspectors should always ask permission before entering bedrooms, especially if residents are out.
- Some residents would like to visit the HIQA offices to better understand its role.
- Information to explain inspections would improve people's understanding.

Key feedback on what happens after an inspection

- Some residents have access to inspection reports, but some do not.
- Reports should be in easy-to-read or alternative formats.
- Residents would like to know more about the post-inspection feedback.
- Staff should read or explain relevant sections during their house meetings to support access.

Key feedback on resident's rights

- Residents showed strong awareness of their rights and emphasised the importance of having them respected.
- Residents expressed a desire for more involvement in decisions that affect them.
- While many residents feel their rights are respected, they feel there is room for improvement in areas such as privacy, independence and decisionmaking.

Other key areas important to residents

- Residents shared key topics, including how they spend their time and the activities they enjoy.
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- Residents appreciated the forum and the opportunity to engage with HIQA.

Published by the Health Information and Quality Authority (HIQA).

For further information please contact:

Health Information and Quality Authority Dublin Regional Office George's Court George's Lane Smithfield Dublin 7 D07 E98Y

Phone: +353 (0) 1 814 7400

info@hiqa.ie www.hiqa.ie

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