

RESIDENT FORUMS

**IN CENTRES FOR PEOPLE WITH DISABILITIES IN
2022 and 2023**

June 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 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.

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Message from the Deputy Chief Inspector



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

One of the most important sources of information for HIQA which informs how we do our work is feedback from people with disabilities who live in designated centres. This report sets out what residents told us over the last two years through a series of meetings with resident forums and a survey.

Residents' rights were a focus for us throughout all of our work in 2023, and we asked them about their rights during the forums. We also asked residents about their experiences of the provision of respite care, HIQA inspections, safeguarding and how information was shared with them.

The feedback also highlights that residents were happy with a number of the actions that we had taken following our report on the 2021 forums. For example, the introduction of a 'nice to meet you' document. In 2022, based on resident feedback the previous year, we also returned to face-to-face forum meetings, holding 15 meetings.

However, quite a few residents also highlighted that management had not given them copies of the previous reports about residents' feedback published by HIQA. They said that they were not always aware of the reports we published about their feedback and the actions we have taken in response to that feedback. It is my hope that the residents' feedback in this report will be shared with residents in all designated centres, in a way that aligns with their communication preferences and support needs.

I would like to thank all residents who took part in the resident forums and gave us their feedback through the survey. I would also like to thank the staff in centres who supported residents to participate.

A handwritten signature in blue ink that reads "Finbarr Colfer". The signature is fluid and cursive, with a long, sweeping tail.

Finbarr Colfer
Deputy Chief Inspector of Social Services (Disability)
Health Information and Quality Authority

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) during a series of resident forums in 2022 and a survey in 2023.

While the Health Information and Quality Authority (HIQA) meets with people living in services on inspection, these forums provide an opportunity for residents to meet with us and share their views outside of the inspection process.

During the 2022 meetings, 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 resident forums and the reports that we produce. We would like to thank the sample group of residents who participated in the resident forum survey who provided crucial feedback so this report could be better presented and distributed to residents across Ireland.

2. How we gathered the information

HIQA engages with groups of residents in designated centres for people with disabilities to better understand the lived experiences of people living in residential care and for residents to provide feedback on their experience of the inspection process. We call these 'resident forums'.

In 2022, we identified 15 forums to meet with across Ireland. To prepare for the meetings, an information pack was sent to service providers by email. This included:

- an information sheet for residents about the purpose of the meetings
- a link to a video explaining what the meeting would be about
- accessible consent forms
- a 'nice to meet you' document introducing the people who would be attending the forum.

While some providers shared this information with residents, some residents we met with told us that they had never seen the video or information leaflet, but would have liked to before the meeting.

In total, we held 15 face-to-face meetings with resident forums. This was a departure from our 2021 meetings, which were held virtually due to public health restrictions around COVID-19. Some of the residents at the forums were supported by staff members to attend and participate in these meetings.

When we met with residents, we wanted to gather residents' feedback on how regulation supports them in their lives, particularly in the areas of:

- Human rights
- Respite provision
- HIQA inspections
- Safeguarding
- Information sharing.

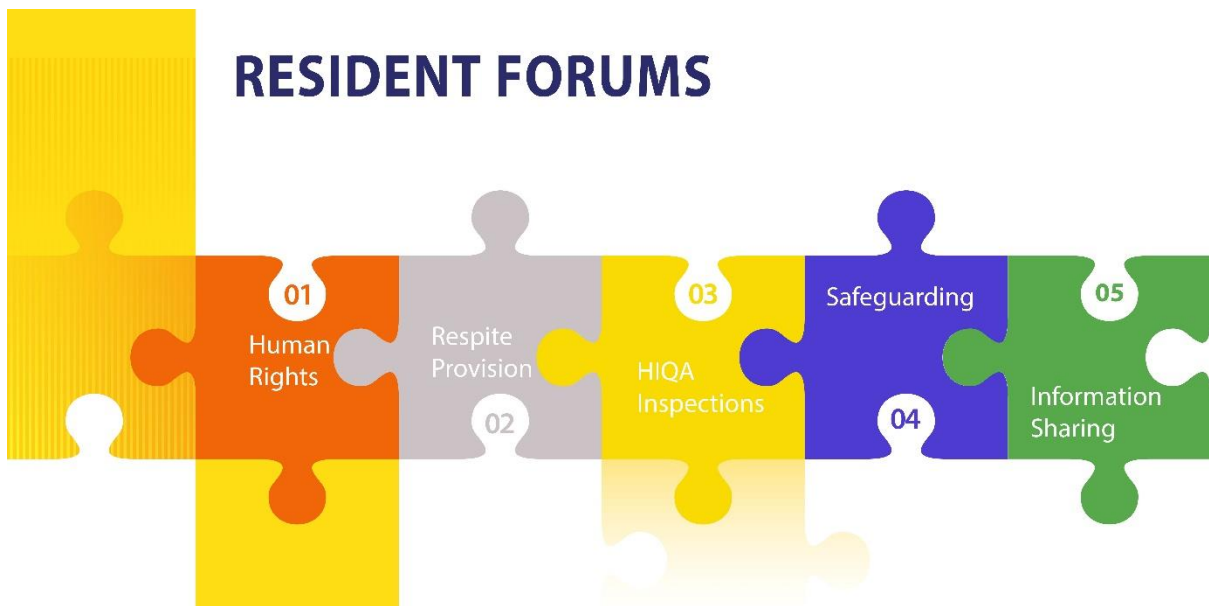
Similar to previous years, a semi-structured interview was used to help us gather residents' feedback in a consistent way. A semi-structured interview is a meeting where the interviewer asks open-ended questions rather than a formal list of questions. Two HIQA representatives were at every meeting. We wrote down what residents told us during the meetings.

The following chapter of this report provides more detailed information on each of these key areas identified by the resident forums.

3. What residents told us

In this chapter, residents' views will be shared under a number of headings:

- Human rights
- Respite provision
- HIQA inspections
- Safeguarding
- Information sharing.





3.1 My rights

In the forums residents told us what rights meant to them and how important they are. The majority of residents understood what their rights were and gave us examples. Some of the main themes that came from this discussion were the right to choice, privacy and to be heard.

One resident described human rights as:

“to be happy”

Other residents described human rights as:

“You can do your own thing, no one will stop you”

“If there was something I was interested in but staff weren’t happy, I’d just let the staff know exactly that it’s my choice and I’m in the right”

“being respected”

“Independence”

“treated equally”

One resident said that they did not know anything about their rights:

“I don’t know anything about rights”

3.1.1 Advocacy

A number of residents were part of advocacy groups. Those residents spoke of the work they do as advocates and why they do it:

"The group want to take actions on issues that are important to people"

"standing up for other people"

"spread the word advocacy"

"I write to politicians and lobby... more money, prescription charges, to get Christmas bonus, fix footpaths – 'Make Way' campaigned for wheelchair users"

3.1.2 Choice

When speaking to residents about their rights, resident in all forums discussed the importance of choice. They highlighted that it was important that they were consulted with and that their choices were respected.

"what we do everyday, we all have choices. In the choices we have rights"

Residents told us about their choice of meals and mealtimes. All residents who spoke about meals stated that they have choice of what they eat and one resident forum stated that the meal plan for the week is discussed at their weekly resident meetings.

"I choose my own food"

"take away on a Friday"

"can go into the kitchen anytime you want"

"what I want for my dinner"

"sometimes I don't like the meals, I tell staff and they help me"

Residents discussed being involved in the day-to-day tasks in the house such as:

"cooking the dinner"

"going to do the shopping"

"washing my clothes"

They also discussed what rights mean in their day-to-day lives:

"I have a right to go down town"

"right to downtime and leisure time"

"the right to stay at home"

Residents spoke of their rights to make choices around going out for coffee, enjoying meals in restaurants and going to concerts. Other activities resident spoke about having the right to do were:

"go out for a walk"

"going on holiday"

"You can choose what you want to do, nice things. Choose to go for a drive or a café"

"I like to make my own choices, where to go... use [voice assistance] to pick music"

Many residents emphasised that it is their right to choose when they go to bed and what time they get up in the morning:

“don’t need to tell me when to go to bed, I go myself”

“I want to get up when I want to get up”

Residents spoke about the importance of having choice in how their homes were decorated, for example when their homes were being painted and renovated.

“We picked our own paint colours for bedrooms and bed clothes”

However, some residents also discussed what happened when they had to move house without consultation:

“No, when I moved house the managers came and talked to me. They found us a house but never asked us if we wanted to live there”

3.1.3 Privacy

Residents in designated centre have the right to have their privacy respected. In the forums, residents spoke about taking private phone calls, their doors being knocked on and having their own room or space.

Residents highlighted a number of positive actions that can be taken to respect their privacy:

“Staff knock on the door before coming in”

“I want my own room”

"Giving me space"

"I have private space downstairs"

Residents also shared negative experiences which impacted on their privacy:

"When I was in other houses there wasn't a lot of respect from staff – they didn't knock on the door. Then I moved to a new home and there's a lot more respect. They knock, ask you what you want to do. Choices are respected now"

"I don't like someone to be listening when talking to someone, especially if it's private"

"if staff are there all day and all night. You don't have your own independence"

3.1.4 Finance

Residents spoke of their right to their own money.

"right to my own money"

"It's your own money"

"I want to get a job and be paid"

3.1.6 Staffing

Residents also highlighted the impact that staffing can have on their rights, for example the importance of having staff that are familiar with the residents.

"Regular staff is important"

"some staff are agency but they don't know me"

Some residents had the opportunity to be involved in the recruitment of new staff;

"We got to be on an interviewing panel for staff. I love it"

And others spoke of the impact staff being too busy has on them;

"Asked to be brought in the bus and they said no cause they didn't have time"

"some staff don't have time to respect us and they are too busy doing paperwork"

"There does be too much paperwork. Years ago, there was one report at night-time. Now there's loads, a big long thing. I have to give staff credit, they are working top to bottom to do what HIQA tell them"

3.1.7 Safety

Residents emphasised the right to feel safe and be kept safe.

"Right to safety"

"to be safe in your own house"



3.2 Respite provision

The majority of residents who took part in the forums were not currently availing of respite services, which meant it was not a topic discussed at all the forums. However, other groups spoke of their experiences being in a respite service.

When residents were asked how they would describe being on respite, they said:

"it's kind of a holiday really- away for three nights, ... really enjoy it"

"I saw it as a holiday"

"I feel safe in respite, privacy is very important"

"We have a bit of fun and everything"

Respite staff were described as:

"very nice, very understanding, very pleasant, they give you a good welcome"

Two residents spoke of experiencing fire drills when on their respite.

"sometimes the alarm's going off, I'm half asleep"

"We hear the alarm and we have to go out the door. You meet at the wall"

Residents spoke of not knowing who they will be on respite with and not getting on with some of the other respite residents.

"You don't know who it is going to be until you are there. Sometimes it's a surprise, you don't know until you show up"

"I would like to be in with the quieter people"

"I didn't like it in with some people"

When discussed if residents had someone they could go to if they wanted to be in respite with a particular person:

"I could say it to the manager"

Residents who lived in their centre on a full-time basis were asked how they felt about respite residents coming into their homes:

"It would be nice [for] only us [to] be there"

When speaking of respite, residents spoke of the activities they enjoyed doing:

"I had pizza at night"

"some have Netflix so you can watch great action movies"

"I buy presents for Mammy when in respite"



3.3 Inspection process

The majority of residents we met had experienced their centres being inspected by HIQA and been present during an inspection. When asked what happens during the inspections in their centres, residents described the inspections as:

“just to check that everything is safe and it’s running okay and everything is grand for you”

“they basically look around to see files and everything to see of everything is ok”

“They go around and inspect all houses – keeping us happy, keep us safe”

We asked residents for feedback on what they would like to see HIQA inspectors do differently when they come to their centres do complete an inspection. Residents told us:

“I would like to look at my folders with the inspector”

“one-to-one chat in private with me”

“use pictures to help people understand your questions”

“you need to involve us more in the inspection”

“If we could get to talk to you (inspectors) more we would be grateful”

"don't like them going into my bedroom, sometimes two people"

"always ask permission"

"would like to be there"

"would like to come around with the inspector for the day"

Residents spoke of how they felt about the inspection process:

"When you first came it was never ending. I remember staff would be under pressure to get all the folders done for you but now it's much easier when we know you are coming"

"When they came it was great, I showed them around the house. They were very polite and they went through a lot of folders and things to check that things were right for all the other clients and for staff. Amazing"

"when they know HIQA are coming they get maintenance in to do all the jobs. When we ask it takes weeks"

"want to show them the jobs I do around the house"

"To be honest I'm glad that they're doing that and checking that it's a great way to ensure whatever it is that it's happening and that its done the right way"

Many residents spoke about inspections being announced or unannounced:

"we prefer when we know ye are coming"

"I don't like inspectors in. I would like to have notice"

"unannounced, don't like it"

"we want to know who's coming"

"I feel unannounced visits are very important, feel HIQA should come more often"

Residents described the inspection reports as:

"hard to understand"

"report can be complicated"

Regarding the residents' views section of the report one resident stated;

"too much information – show respect... privacy is better"

When asked if they would like to see the HIQA report, one resident told us:

"It's mostly about them (staff), not us, so no...it's kept private"

There were a number of residents who stated they do not get to see the inspection reports on their centres.

"They keep the report private"

"don't read it to me"

"staff don't come back to say how we got on"

"I don't know about the report"

However, some residents said that the report was discussed with them:

"I know you send the report back. The person in charge talks to us and reads it"

"We do find out after how the inspection went"

We asked residents how the inspection reports could be made more accessible. Residents suggested:

"bullet points"

"pictures"

"a recording people could listen to"

"audio form to listen to"

Some residents spoke of the benefits of an inspection and the improvements made to their homes:

"I got my room done up after HIQA"

"we got new fire doors"

"more staff in the centre since HIQA called"



3.4 Being safe

"we have the right to feel safe in our house"

We asked resident what being safe meant to them. They said:

"I have my own room"

"Lock your door"

"I don't answer the door"

"checking peoples identity when they come to my house"

"My support staff, my comfort chair, hoist, regular staff, my own space when I need it"

Road safety and having to negotiate getting to buses was discussed as it can be dangerous for residents. They emphasised the importance of appropriate bus stops located near the houses to keep residents safe.

"Not knocked down by a car"

One resident told the forum of training they had received that made them feel safe:

"I did fire extinguishers training"

Residents spoke of the actions they would take if they did not feel safe.

"talk to staff if I feel worrying about something"

"we have a meeting every Friday and we talk about it then"

"I would complain to the manager"

"I would let my staff know straight away"

Residents told the forum how the change in staff impacts their feeling of safety in their homes:

"I don't feel safe cause staff keep leaving"

"some staff are agency we prefer regular staff"

Overall, the forum had positive things to say about staff:

"one thing about staff, they are very nice people, they're lovely people"

3.5 Information sharing

Residents spoke to the forums about the importance of information being shared with them. This included their personal files, access to those files and what information is within them.

"We are allowed look at our file"

"Yes, if I want to read my file, I have to ask someone to help me"

"I keep my own folder in my room... my goals... my holidays"

"GP, dentist, Mam and Dad's phone number, all about family and me"

When asked where information is received or shared with residents, we were told:

"Resident meetings – we talk about visitors we are asked how we are getting on"

"staff give us the information if you ask"

Another form of information sharing is having the information on display, or filling in questionnaires to give feedback to staff.

"notice board"

"We fill in questionnaires"

Residents also discussed the challenges of information being shared with them, and the need for information to be made easier to understand.

“very difficult for me if someone talks fast”

“It’s so important to make it in a way that we can be ensured of exactly what it is and be informed and shown information in a way that will help us all”

Residents made a number of suggestions as to how information could be made easier to understand. These ranged from using a larger font size to speaking slower to more specific tools.

“Bigger writing”

“staff photos so we know who is on duty”

“social stories for fire drills and evacuations”

“I do easy reads”



3.6 Other feedback

Although it was not a theme for discussion at the resident forums, residents wished to talk to us about COVID-19, and the impact that the pandemic had on their lives.

One resident told us how difficult that time was:

“stay at home for two years ... very upsetting and heartbroken over it. I didn't like it. Very upset about it”

Another resident had trouble understanding what it was, but said that staff helped them understand:

“I didn't understand it so I had to ask – they got a piece of paper and made it bigger for me and that helped”

Residents discussed how COVID-19 impacted relationships, friendships and attending activities.

“I wouldn't be allowed visit her cause of the COVID. I would love to see her”

“Use to have advocacy group... it stopped with COVID but it was a very good idea”

One resident also highlighted that the balance of safety and understanding was a challenge:

“Balance between being able to hear and being safe” (in relation to staff wearing masks.)

4. Next steps for HIQA

The feedback we received from residents through these forums is a valuable source of information which will inform HIQA's work going forward. We would like to thank all residents who took part in these forums for their welcome and for sharing their thoughts and opinions with us.

Given residents' feedback on the accessibility of information and communication with them, we will engage with providers on this issue to highlight the importance of ensuring residents can access communication and information support.

As previously mentioned, in 2023 the resident forum working group conducted a survey where a sample group of residents provided their feedback on previous resident forum reports and what can be done better going forward. The feedback received was that the reports were not reaching the target audience, as the majority of residents had not seen the published reports.

Residents told us that a poster with the key messages from the report would be an appropriate step to take as it could be displayed in centres for residents. A poster has been developed and is being distributed to each designated centre.

HIQA will continue to meet with residents outside of the inspection process to listen to their views and to incorporate this as learning.

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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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