

RESIDENT FORUMS

IN CENTRES FOR PEOPLE WITH DISABILITIES IN 2021

OCTOBER 2022



Safer Better Care

About the Health Information and Quality Authority (HIQA)

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

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

Table of contents

About the Health Information and Quality Authority (HIQA).....	2
Table of contents	3
Message from the Deputy Chief Inspector	4
1. Introduction.....	6
2. How we gathered the information.....	7
3. What residents told us.....	9
3.1 My rights.....	10
3.2 My home	17
3.3 My community	26
3.4 The inspection process	34
3.5 People who are important to me	38
3.6 Impact of COVID-19.....	43
4. Conclusion	46

Message from the Deputy Chief Inspector



Finbarr Colfer, Deputy Chief Inspector of Social Services

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. A core aspect of our inspections is to spend time with residents, to listen to what they have to say and to observe what their day-to-day life looks like.

We also want to listen to the views of residents outside of the inspection process. Over the past number of years, we have arranged for our staff to meet with residents in their own groups, where they have their own supports and where they feel comfortable speaking with us. In 2021, due to the ongoing public health restrictions due to the COVID-19 pandemic it was not possible to meet in person as we had in 2019 and 2020. However, we continued to meet residents' groups through online virtual meetings.

This report sets out what residents told us during those meetings. The feedback from residents reminds us, as inspectors, about what is important in the lives of people with disabilities living in designated centres. Often, the things that are most important are the things that many people take for granted – things like being able to spend time in your own home without having to live with excessive noise, such as shouting, especially in congregated settings or being able to meet other people in the community and participate in activities, such as doing your own shopping, going to the local pub or joining local groups such as walking clubs.”

In this report, residents have told us about what matters to them and impacts most on their life. They told us about the difference between living in a large institutionalised residential service and the improved quality of life for them when they moved to small, local, personalised homes in the community.

Listening to the views of residents ensures that we continue to focus on the requirement for providers to uphold the rights of residents and that the will and preference of people with disabilities are respected. We also hope that by publishing this report, others will also listen to the views of residents and ensure that these are used to inform their work also.

Finally, I would like to sincerely thank the residents who invited us to join them in their meetings and for sharing their views with us in such a powerful way.

A handwritten signature in black ink, appearing to read 'Finbarr Colfer', with a long, sweeping flourish extending to the right.

Finbarr Colfer

Deputy Chief Inspector of Social Services

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 2021.

While inspectors from the Health Information and Quality Authority (HIQA) meet 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.

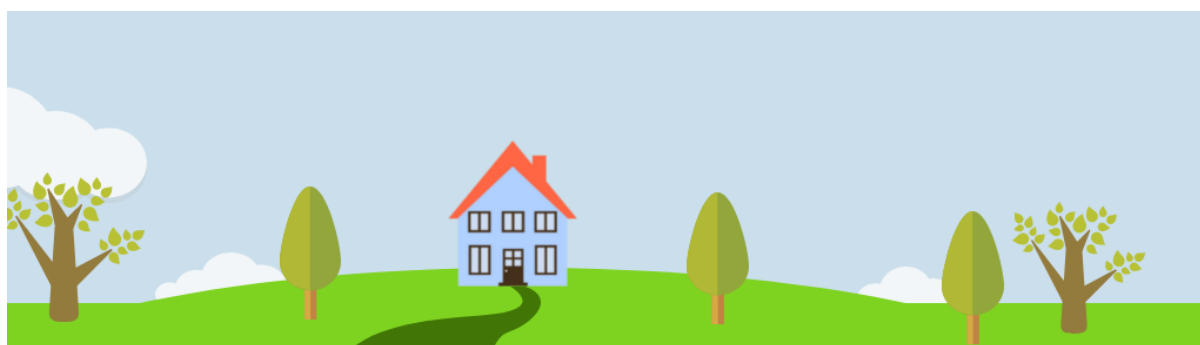
In 2021, we met with 80 residents during 22 online meetings.

2. How we gathered the information

In 2019 and 2020, HIQA engaged with residents' groups from 18 different parts of Ireland to understand their experiences of living in residential care, and the impact of regulation on their lives.

Residents' feedback was presented in a 2020 report on *Disability Services Resident Forum Meeting*.¹ It detailed how residents living in congregated settings² have a poorer quality of life than those in smaller, community-based settings.

HIQA committed to continuing to engage with groups of residents in designated centres for people with disabilities in 2021. As a result of the previous feedback, we wanted to speak with residents in more detail about how their lives have changed since moving from larger institutionalised settings to smaller homes in the community.



In May 2021, we wrote to all providers of disability services which are currently registered with HIQA, asking them to put forward the names of residents' groups who wished to engage with us as part of the 2021 residents' forum. Responses were received from 16 providers.

We identified 22 groups to meet with across Ireland. To prepare for the meetings, an information pack was sent to providers by email. This included:

- a link to a video with a HIQA staff member explaining the project and what would happen during the meeting. It offered an opportunity for residents to see the person from HIQA who they would be talking with on the day.
- an information sheet for residents about the purpose of the meetings

¹ <https://www.hiqa.ie/reports-and-publications/key-reports-and-investigations/disability-services-resident-forum-meetings>

² Congregated settings are where 10 or more people with a disability live together in a single living unit or are placed in accommodation that is campus based. Health Service Executive. Time to move on from congregated settings - A strategy for community inclusion. 2011.

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.

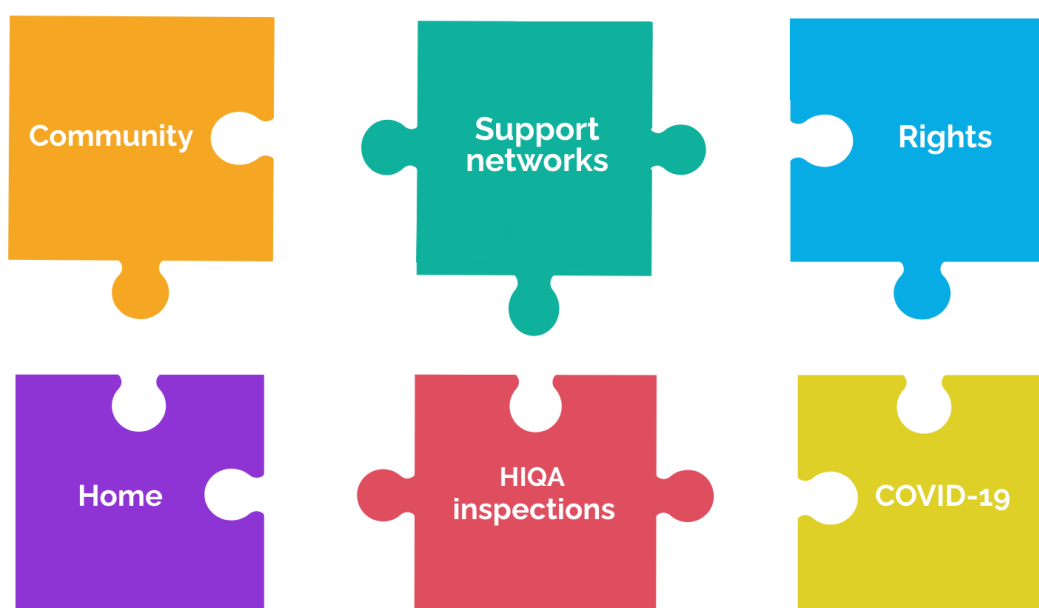
Due to public health restrictions around COVID-19, we met with residents virtually in 2021. In total, between September and October 2021, we held 22 online meetings with 80 residents. Some residents were supported by staff members to attend these meetings.

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

- Rights
- Home
- Community
- HIQA inspections
- Support networks
- COVID-19.

Similar to the 2019 and 2020 resident forums, 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 residents groups.



3. What residents told us

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

- Rights
- Home
- Community
- The inspection process
- People who are important to them
- Impact of COVID-19.

We asked residents a number of questions about their rights and homes with a focus on living in or moving from congregated or campus-based settings. Residents who had previously lived in campus-based settings, told us that life was far more positive for them since moving to their new homes in the community. It is important to note that many residents who have moved from a campus-based setting spoke very highly of the staff who supported them in those campus-based settings.

Furthermore, many residents brought up how COVID-19 had impacted on their lives since early 2020. The impact of COVID-19 could be seen in multiple areas, such as restricted access to the community, limited interactions between inspectors and residents due to social distancing and mask wearing, and an increase in technological ways of keeping in touch with their family and friends.

Their experiences during the pandemic have been detailed under each section as appropriate, along with a final section on the overall impact of COVID-19 on their lives.



3.1 My rights

People living in designated centres have a number of rights, including the right to:

- be safe,
- be respected,
- be involved in making decisions
- privacy
- and see what is written down about them.

Residents should be supported to know and understand their rights, and to make a complaint if their rights are not upheld.³

When we met with residents, we spoke with them about what their rights meant to them. Residents told us:

“I have the right to be respected, right to my opinions, right to speak up, right to my own space and to treat people how I would like to be treated”.

“We have the right to feel safe, have privacy and dignity”.

“Having your independence.”

“We have the same rights as everybody else”.

Knowing their rights

Some residents found it difficult to understand what their rights were.

Staff who were supporting residents in one focus group explained to us that while it is difficult for them to know at what level residents understand their rights in full, they endeavour to support residents in doing so, by providing them with easy-to-read information and explaining to the residents in detail about their rights. We

³ HIQA's *Guidance on a Human Rights-based Approach in Health and Social Care Services* (2019): <https://www.hiqa.ie/reports-and-publications/guide/guidance-human-rights-based-approach-health-and-social-care-services>

heard that while independent advocacy is available to many residents, due to limited resources, that an independent advocacy organisation is only available to residents when a problem arises. One resident told us that they were completing courses so that they could become an advocate for others.

We heard how residents' rights are discussed at resident forums run by some services, as well as at meetings in residents' homes. Some residents told us how staff support them to learn about their rights.

"Have meetings with staff and clients, talk about abuse, how to be careful and how staff can help."

"We talk about rights at meetings. I do find it good. I know my rights."

Residents in one focus group told us that how they were part of a rights committee within their organisation and that they actively take part in discussions about rights, including making decisions about where to go on their holidays. During another focus group, one resident held up the charter of rights to show us. Staff explained that this resident holds this charter during every advocacy meeting, which are held monthly within that service.



If residents were unsure about something to do with their rights, they knew where to ask for advice about it. One resident explained that they can ask for support if they need it, and staff will assist. For some residents, knowing about their rights meant that they knew that they could make a complaint if they were not happy about something.

"If I need to make a complaint, I tell someone."

Residents told us about what rights meant the most to them. These included, having a house, being supported to do what they want, and having control.

For example, one resident said that rights meant having their own apartment, while another resident referred to their right to have their own home. One resident showed us a photo of them being supported to vote, and to them, this meant that their rights were being upheld.

Residents also referred to the role of their support staff in upholding their rights.

Some residents told us that having control over their own money was important to them. For one resident, this was something that was new to them since moving from their previous home. This resident did not know who had control over their money in their previous home.

“Didn’t have money when I started here. I have my book now.”

Another resident said that looking after their own bills was important to them.

“I look after my bills.”

However, not everyone felt that their rights were upheld. One resident told us, “I’ve no control over my life.” This resident said that they spoke with the service about this and that they have an advocate. They told us that while they can choose meals and where to go on a day out, they would like more control over how care is being provided to them.

Right to access personal information

We spoke with residents about their personal information and asked if they have access to their personal files. Some residents told us that they have full access to their files and that they get updated regularly and other residents told us that they have never seen the folder which contains their personal plan.

“I look at my folders. Has things like behave, diet, and health.”

“I don’t look at them at all. I have two folders, one red and one blue.”

One resident outlined that while they know they should have access to all information about them and that while they have access to their folder, accessing other notes about them is not always facilitated.

“Have a right to read my folder. I have a personal file, but I am talking about other notes.”

During one meeting, we heard how the annual meeting to review residents’ personal plan was not meaningful for all residents, with one resident describing it as “a tick-box exercise.”

Furthermore, some residents told us that at the moment they do not have their monthly meetings and cannot remember the last time they had one.

Being involved in decision-making

“You have your own rights to do your own thing.”

The right to choice and to be consulted about decisions was emphasised by residents on a number of occasions. Residents told us about how important this was to them.

“I make my own decisions.”

Residents told us how they like to have the choice to do their own chores, such as their laundry, shopping and paying their own bills. Many residents told us how they are supported by staff in having time to make choices and decisions.

“We go through choices about who will do the shopping.”

“The staff are very good help...and the staff help me to make decisions.”

The majority of residents we engaged with told us of how they were supported by staff to make choices around what they wished to have for their meals. We heard how staff help residents to make choices around what food to have, with one

resident referring to a 'scrapbook', which they have in their room to help them to decide what dinner they would like to have.



Some residents told us that they have meetings one evening in the week, where they talk about what meals they would like to have for that week. We heard that some residents enjoy getting takeaways. Another group of residents told us that they were going to make potato bread the next day for their meal.

Other residents told of the things that they discuss at their weekly house meetings. When we asked residents if they felt that staff listen to what they have to say, some residents said yes, and that this is important to them as they feel they are consulted with about decisions to do with their lives.

"I feel I have a good bit of choice in life and at home."

Residents spoke about consulting with their friends who live with them about the chores that each of them do around the house. They told us how this was important to them.

"We have weekly meetings where we agree on things like cleaning and what we want to do."

Residents told us that the right to make choices about how they spend their time was important to them and for some residents we spoke with, it was clear that their preferences were respected. For example, one resident told us that they were supported to take part in at least two planned activities each day.



Where residents needed guidance or reassurance about making their weekly plan, staff supported them to make these decisions. One resident said that staff supported

her to choose her own day service. Another resident told us that they have a weekly planner and that they give this to staff and staff support them as per that planner.

"I make a daily plan with staff."

"I tell them what I am doing with my day."

Some residents spoke about not being able to leave the house when they choose, due to there not being enough staff available to support them and that staff think they will get lost or get into trouble. This lack of independence bothered the resident.

The choice not to take part in certain activities was also important to residents. We heard from one resident who decided to give up horse riding because they did not enjoy that activity anymore.

However, some residents felt that they did not have choices and lacked control over their daily life. One resident said:

"I don't feel I get to make decisions... I have no control over my life."

This resident said they had highlighted the issue with staff, and said that they were unable to choose how care is provided to them. However, they can choose meals and if they would like to go somewhere on a particular day. Other residents living in this service said that they would like to be involved in the development of policies that impact their lives and to see those policies when they wish.

One group of residents told us about how they were consulted about plans to renovate their home. They had lived together for a very long time, with two residents sharing a bedroom, and there are plans to build an extension so that they can continue to live together but have their own rooms. We heard how residents were involved in the drawing up of plans for their new home.

"We are happy to get our own bedrooms and a new bathroom."

Some residents told us that moving from a large congregated setting to a community-based home meant they now had greater choice:

"I get choice when to go out."

"I prefer it here."

3.2 My home

Following on from the *2020 Disability Services Resident Forum Meetings* report, we wanted to speak with residents in more detail about their experiences of living in larger institutionalised settings, and how their lives have changed since moving from congregated settings to smaller homes in the community.

Living in congregated settings

Residents who were still living on campus settings told us about their experiences. It was evident that for some residents who live in campus-based settings, the experience is not a positive one.

“Want to move closer to home.”

“I am (over 50) years...not happy with the place... get out of [campus]...fed up staying in one place.”

“No private bathroom.”

When we asked one group of residents what life was like for them in their current home on a campus, we were told:

“Feels like years in jail without shooting anyone.”

One group of residents told us how they are less involved in their local areas and communities than their friends who live in smaller houses in the community. They told us that they do not have as much opportunity to get out and about in their communities as they would like, due to staff shortages. Residents explained some of the reasons for this:

“Not all staff have time.”

Residents told us that they would like to get out of the campus and live in the community, but that there is nowhere for them to live on their own.

“Hard to get out of [campus name]. There is nowhere to go, to live by myself.”

We also spoke with residents who had moved out of large campus homes, into the community. They discussed the difference between the two types of settings:

“No comparison.”

“In previous home, we didn’t have our own living room. We used to share with other people. Now we have our own living room.”

“Here I have the run of the kitchen. In [congregated setting] the kitchen would be locked.”

“I have my own bedroom and bathroom. Relaxed, I am happy.”



The impact of noise on residents when living in larger congregated settings was discussed in a number of focus group meetings. Residents referred to excess noise, and pushing and shoving in congregated settings, which they no longer experience in their new homes in the community.

One resident who had moved from a campus-based setting to a new home in the community told us that they loved their new home because:

“No noise... No pushing. No shoving.”

Another resident told HIQA that they did not like it in the campus. They explained that this was due to "...teasing, joking and coddling. Couldn't stick it with all the teasing". Everyone we spoke with was happy to have moved to a house in the community.

It is important to note that many residents who have moved from a campus-based setting spoke very highly of the staff who supported them in those settings.

"Nice like, it was a proper hospital...the staff were terribly nice up there."

During one meeting, residents who live in a house where some have to share bedrooms, said they were excited about moving to new homes in 2022. When asked how they feel about the move, residents were very positive and were looking forward to new things, including the ability to decorate their rooms.

"You will have a lot more space."

"I have no television in my room. I would like one in my room."

"I'd like a new bedspread."

"I am going to put blue paint, get a double bed and television up on the wall, and a hook for my coats, and wardrobes."

Living in homes in the community

Residents who had previously lived in campus-based settings told us that life was far more positive for them since moving to their new homes in the community.

They told us that they preferred the community setting, and welcomed the freedom these homes offered.

Most residents said that they were happy with their new homes and they would not change anything about it.

However, residents' experiences of being consulted with or having choice when moving to a new home varied. Some residents told us how they had discussions about their new home, although the choice of where to live was not a factor. Staff explained that this was mainly due to limited supply of housing, which removed the ability to offer choice to residents. One resident told us that they chose to move to the house that they currently live in and that they were happy with this decision. Some residents told us that the decision for them to move to a new home had been made by their family members, without them being consulted. In some cases, the move happened so quickly for some residents that they felt they did not have the opportunity to be consulted.

"No, not at the time. It kind of happened too quickly."

"I just saw this one, but I was happy with it. I just feel that living on my own, I can do what I want."

Residents also spoke about the importance of getting on with the people that they live with and how they would like to meet people who would potentially be moving into their home before it happens. They also wanted choice about who they lived with.

"If someone new was to move in, would like to meet them first."

"Didn't choose to live with who I live with."

During one meeting, staff told us how a transition plan is developed for all residents who will be moving house and part of that plan is to discuss the positives of moving to a new house. The transition plan also involves sleeping over in the house so residents have the opportunity to get used to it before they move in fully.

One resident told us how they like their home, but the physical layout is challenging for them and does not meet their needs entirely, as they find stairs a problem.

Residents in one meeting described their new house as "warm" and "caring", while others referred to it as a "home".

Residents told us about the things they liked most about their new home, with having their own wardrobe being mentioned frequently. Residents spoke about how much it meant to them that they now had a place of their own to store their belongings. Residents spoke about the privacy that their new homes offered them. This was something that many residents did not have while living in larger institutionalised type settings.

“My apartment is my space.”

“I love it here. I love everything. My apartment, the staff,
and my friends.”

During one focus group meeting, a resident became upset when speaking about their time in their previous home, where they shared a bedroom with 20 other residents. We heard how this resident had just bought a TV for their new bedroom, in a home where they no longer had to share a bedroom with others. The joy of not having to share a bedroom was reiterated by many residents, who commented that they enjoyed the privacy and space that this offered them. One resident we spoke with explained that it was the first time in 50 years that they had their own bedroom.

Residents told us about how important it was to them that their homes were personalised to their taste and how in their previous home on a campus, this was not always possible. One resident spoke of how the décor in their previous bedroom was not to their liking. Some residents had lived in congregated settings for several decades and told us of their delight at being able to personalise their bedroom in their new home, to match the colours of their favourite soccer team or with flags of their favourite GAA team.

“One side of the wall is red and the other is magnolia.”

“I chose my room colours in the house. I painted
Liverpool colours in my room.”

For some residents, living in a smaller house made them happier because they had more choice and there was no one to boss them around. Residents explained that this was due to there being too many people, whereas in their new homes with less people, it was much better.

Residents spoke about the freedom that they have in their new home, telling us:

"I am my own boss. No one but me."

"No one bothering me anymore."

One resident told us that they were now able to get a pet of their own for the first time since they moved from a campus. Another resident told us that they had an apple tree in the garden of their new home and that they enjoyed baking with the apples.

It was evident from some focus groups that having living space of their own, or privacy within a shared living space, was important for residents.

When asked if they would ever consider moving back to the campus they previously lived in, residents answered, "no".

"Not going back. Locked doors. Hated that."

Some residents told us that they do go back to visit their friends who still live in a campus setting.

Similar to last year's report, residents spoke proudly of being able to do jobs around their house, such as taking out the rubbish, emptying the dishwasher and keeping their own space tidy. It was important to residents to be able to have a role in the running of their homes. We heard how this was something that they were not able to do to the same degree in a larger congregated setting.

Residents spoke of how they have greater opportunity to go out and do social things outside of their home, now that they live in a smaller house in the community.

"I get a choice when to go out."

"Day trips. Prefer it here...compared to campus living resident could go on day trips."

When we asked residents if there was anything that they would change about their home in the community, some residents told us:

"I'm very happy with everything put in place, I have no problems or issues."

"It's been a great experience for me."

Some staff spoke about the positive changes that they have noticed since residents have moved from larger homes to smaller houses in the community. In one focus group, staff spoke on behalf of residents about the positive aspects of living in a house where there are less residents, particularly where residents' primary communication was not by verbal means.

"With the old structure, it was all on the clock. It's easier now. We have more time for individual residents."

"There is less challenging behaviour because we have more time to spend with residents."

Residents spoke about how important it was for them to live with people that they liked and felt safe with. One resident told us of how they are afraid of one person who lives in their home and how this is impacting their life.

"Staff are helping me. I stay in my bedroom if [resident] is walking around the corridor. I complain all the time."



Another resident spoke about how they would like to live in a female only house, as they are currently the only female in the house they live in.

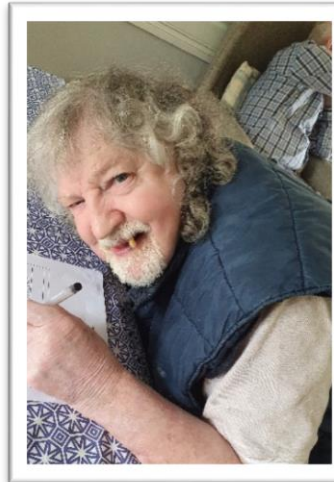
Residents who had moved from larger institutionalised, campus-based settings told us that they like living with less people because it is easier for them to get to know the people they live with, than when they lived in a larger setting. Residents described their previous home as being too crowded. Some residents we spoke with now had apartments of their own, and told us how much they liked having their own space.

"You could live with a load of people and you wouldn't know who some of them were. Much better in a smaller house."

"Like that I don't have to share my space."

"Like the fact that it's my home."

Overall, residents living in smaller homes in the community had a far more positive experience than those living in larger institutionalised settings.



Photos residents shared with HIQA



3.3 My community

Residents told us that being involved in their local communities had been negatively impacted as a result of the COVID-19 pandemic. The level of community involvement experienced by residents we spoke with during 2021 was very different to those we spoke with during 2019 and 2020. For many residents, COVID-19 put a stop to activities that they engaged in, and at the time we spoke with residents the freedom and enjoyment they previously experienced by being out and about in their communities had not fully returned. Some residents we spoke with felt cut off from their communities, due to the various public health restrictions.

“If you met me outside of the centre, I am a different person”.

“Yeah, I had friends in that, but no, not with COVID”.

Residents told us about the things that they enjoyed doing that made them feel part of their communities. One resident said they were part of an advocacy group which was a connection for them outside of their home.



Some residents told us about notice boards which are on display in their houses, which list all of the activities for the week ahead.

“We have a board with all the information on it, over there, our board”.

Some residents told us that their community was their day service and that they have friends there, and this makes them feel connected to their community. One resident spoke about how much they missed their friends when day services stopped during the pandemic.

“I have friends in the day service.”

“We missed our friends there.”

Some residents told us about how they go out to meet their friends in different places, and how this helps to make them feel connected and part of their community. Other residents spoke about how their friends come to visit them in their homes and this helps them to feel connected.

"I see my old friend down town in [town]. We did live together."

Residents spoke of the places that they like to visit in their communities, such as local shops, cafés, the pub and restaurants.

"I love shopping."

One resident told us how they missed going out shopping during COVID-19, commenting:

"I didn't like the lockdown because all the shops were all shut and you couldn't buy anything. I hope there isn't another lockdown before Christmas."

Other residents told us that they enjoyed shopping online and having parcels arrive to their door, while shops were closed.

We heard from one resident who was a member of their local walking group, while others liked to go out walking in their community and enjoyed meeting people while out and about.

"I like to go for walks."

"Out and about. Goes walking with walking group."

Residents told us of some of the other things that they enjoyed doing which are important to them, such as going to Mass, the cinema, wildlife parks, drives and the local farmers market. They said these things help them to feel connected by getting out and about within their community.



We heard how some residents enjoyed going to Nathan Carter concerts, doing karaoke, going for walks on the beach and going for afternoon tea. One group of residents we spoke with told us how they enjoy doing art and crafts and showed us some of the paintings that they created and t-shirts that they designed.

Meeting people outside of the centre and people that they live with was important to some residents we spoke with. We heard from one group of residents how they feel part of their community when they go to the local pubs, coffee shops and restaurants. Some residents told us how they enjoy getting out an about and going to the pub.

“Absolutely brilliant! The pub is just up the road.”

“I feel my decisions are respected and I feel very belonging where I have dinner in the pub.”

“People in the pub are nice and generous.”

Other residents told us about their jobs and how they were important in making them feel involved in their communities. Residents told us “I talk to people up there that I know” and “I have a cup of coffee.” One resident told us, “I like my work.” We heard how having an income from their job was important to one resident who told us, “I get paid once a week.”

Another resident spoke about their work in a garden centre. We also heard about the impact of the COVID-19 pandemic on one resident’s job in a local charity shop and the impact that not being able to go to work had on this resident’s life.

“I felt very cut off. I couldn’t attend work. I was used to getting the bus and train. Everyone else has a car and they could go to work, but I couldn’t.”

This resident felt very strongly about how their work not only meant their independence but also was their identity in a manner and explained that being fully

vaccinated will mean that they can go back to work when the Charity shop opens up again.

“When I was fully vaxxed. That was my golden ticket to get back to work.”

Another resident told us that they volunteer at their local church, and that they are glad that this has returned as it ceased for a while during the pandemic. This was reiterated by other residents we spoke with who worked in various jobs.

“Work in [garage and windscreen repairs]. I like that. I work in a charity shop on Friday’s. We take donations of clothes.”

Residents who had not returned to their jobs since the COVID-19 pandemic forced them to remain at home, spoke of the impact that this has had on them.

“I used to get paid.”

“Since then it’s been very hard for me to get back to it. Infection rates are going up.”

“I haven’t heard anything back from anybody about me going back to work.”

Residents in another forum spoke of how they enjoyed going out and about in their community again since having received the COVID-19 vaccine. One resident told us of the things they like to do, which they were not able to do for a long time due to the pandemic.

“Going out for coffee, walking groups, going out and about with friends.”

Some residents we spoke with told us how they enjoyed volunteering in their communities and how they missed this during COVID-19, while others still maintained some contact with the community during the pandemic.

“Am the marshal volunteer for the parkrun, so missed that.”

“I still go out ... to do my messages and to go for a walk. We wear face masks.”

Some residents spoke of their pride about engaging in their communities through the courses that they are enrolled in, such as woodwork and maths courses. We heard how residents from one service had completed a cookery course and received a certificate for their accomplishments, which they thoroughly enjoyed. Another resident told us that they used to have a job but gave it up to do a college course which they are currently enrolled in.



Day services are a hugely important part in many residents' lives; however these services were severely curtailed during the pandemic. Although some residents we spoke with told us that they do not miss day services and that they actually enjoyed the break, many told us that their day service was their social outlet, the place where they meet friends and do various activities that they enjoy. The distress that some residents felt because their day services were closed during the pandemic was evident. Some residents we spoke with told us how some of their day service was run over virtual online meetings, but that they miss the social aspect of going out each day to attend their day services in person.

“I miss my day service. I want to go back. I miss my friends.”

When asked what residents missed most during COVID-19 restrictions, one resident told us, “I would like to go back to day service.” We heard that some day service staff had been redeployed during the pandemic to maintain an interest in activities and maintain social interactions for residents when restrictions were in place. While

this was a positive move, the experience was not the same for residents as attending their usual day service.

In some services, existing support staff made huge efforts to get residents involved in activities within their homes, when they were unable to go out. Residents told us about some of the activities that they did at home during the various lockdowns, some of which are continuing.



Some residents learned how to cook and bake during lockdowns and they are continuing this as they enjoy cooking with staff. Staff supporting another resident explained that the resident loved to feed the birds in the garden and that this became a favourite pastime during lockdown.

During one forum meeting, we heard about a friendly betting competition that residents had in place between houses for sporting events. Staff told us of the resident's love of sport and that he and residents in another house had a friendly competition in place during COVID-19.

During one meeting, we heard how one resident really enjoyed going to McDonalds and while this was not possible due to COVID-19 restrictions, the resident's support staff recreated his favourite McDonalds burger at home by having a BBQ in the house with the other residents. It was evident from this resident's facial expression that this was something that the resident really enjoyed and appreciated.

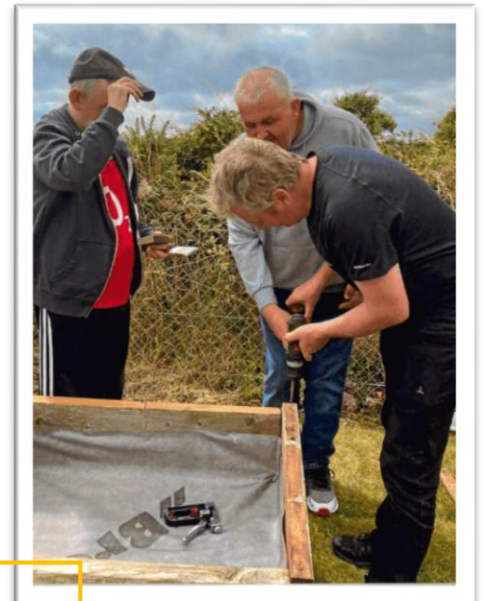
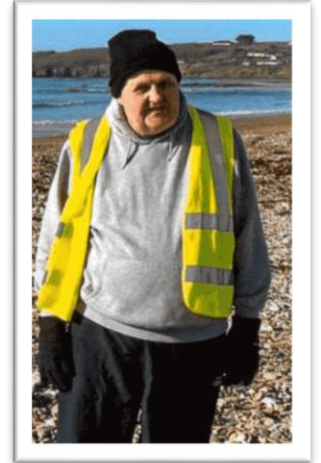
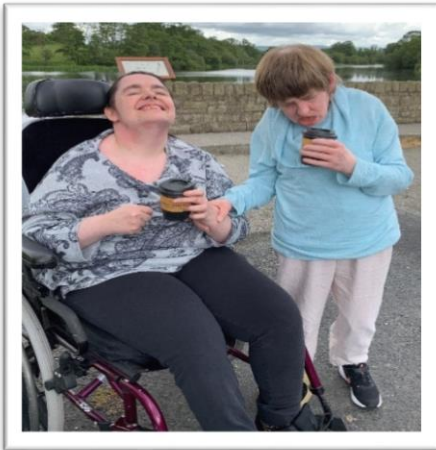
Staff in one service, who were providing feedback on behalf of residents who were present with them at the meeting, told us how they also created a Halloween and Christmas experience for residents in their homes, in the absence of residents being able to go out to soak up the atmosphere themselves. We heard how staff created a winter wonderland cabin in the garden of one house and residents visited this and had photos taken, which we saw during the forum meeting. We heard how a café was set up in another house and residents were able to visit the café and replicate the experience of going out for a coffee as best as possible. Some staff told us that they arranged international cuisine nights where residents and staff would cook foods from various countries and residents enjoyed a meal together, like in a restaurant.

In contrast, another resident told us how they missed going to their woodwork classes. Another resident said that they missed being involved in the Special Olympics.

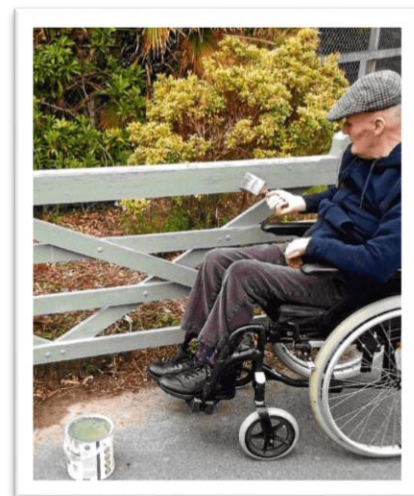
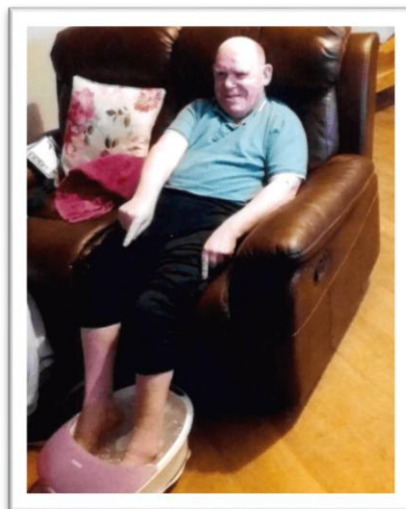
For some residents, the social activities that they had engaged in before the pandemic had resumed. For example, one resident was attending Tidy Town meetings. Another resident we spoke with had recently gone to see a concert. However, for other residents activities had not returned. One resident told us that he was looking forward to going back to soccer so that he could meet his friends.

"I want to go back to soccer training with the lads and cheer us with them."

While community involvement had changed for many residents during the pandemic, many residents were optimistic and looking forward to the things that they planned to do as restrictions eased, including planning holidays such as glamping trips and having outings with their friends again. Residents told us about the things that they were most looking forward to when restrictions allowed. For example, one resident told us that they plan to take up golf when the restrictions lift.



Photos residents
shared with HIQA



3.4 The inspection process

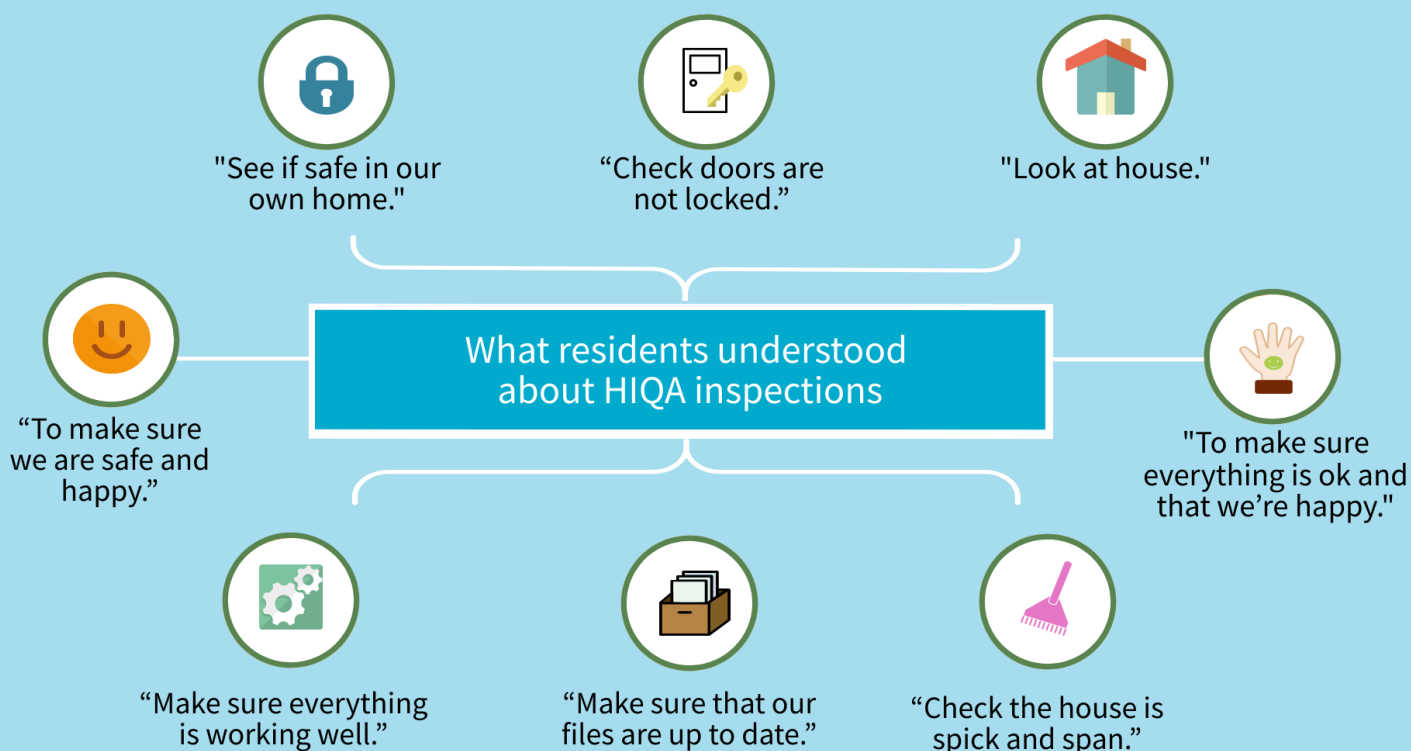
"HIQA are welcome."

"HIQA have rules...emergency lights, training. Much safer now."

"HIQA are there to make sure we are safe and that staff are doing a good job."

We spoke with residents about HIQA's inspections and the role of HIQA.

Residents told us what they understood about HIQA's inspection process and why we carry out inspections.



Some residents we met with told us that they liked when HIQA comes to visit them in their homes. When asked about whether they liked inspectors visiting their home, some residents said they do.

“Normally I look forward to the visit. I can tell them things that worry me or that I don’t like.”

While some residents did not know why HIQA inspectors visited their homes to do inspections, they pointed out improvements that had been made as a result of the inspection, including getting their home painted, additional staffing or better access to all parts of their homes.

“Got all painted and done up with pictures.”

“We got new staff after the inspection. They are very good.”

“The lock was taken off the office.”

However, other residents said nothing changes following inspections. One resident said inspections were a “tick-box exercise”. They felt that if they said something negative to an inspector about their experience of living in their home, it would be brought to the attention of the management and they would end up regretting saying anything about it. As a result, they felt reluctant to share any concerns that they might have.



While some residents enjoyed speaking with HIQA inspectors when they came to visit their homes, we heard that for some, the 15 minute time limit that existed as a result of COVID-19 public health measures was not working for them. One resident said they had to prioritise what they wanted to say to the inspector to fit it into the time allowed. Other residents said they would have liked more than 15 minutes to speak with inspectors and to show them around their homes. However, most understood that this time limit was due to limitations brought about by COVID-19.

Another resident explained that they are aware that if they have any concerns about their service, "We know we can contact HIQA." This was echoed by another resident who told us, "we can call HIQA if something is wrong", but said "but we talk to staff first."

Some residents told us that they would prefer to speak with inspectors alone rather than in a group, when they come to visit their homes.

We heard from a resident about their experience of talking with an inspector when they carried out an inspection of their service. This resident told us, "Inspector talked to me in a lovely manner". Other residents also spoke highly of the HIQA inspector who visited their home, saying:

"They were lovely. They listened to me."

"Ye are very good at making people feel at ease."

Residents explained what happens when HIQA inspectors come to visit their homes.

"They introduced themselves at the door, showed us their ID before they came in and sat down and talked to the manager."

"They asked us would we mind if they went through our folders."

"They would say, 'well done on this, well done on that'."

Residents in one group said that they like to know when HIQA is coming to visit in advance so that they can meet the inspectors. Many residents we told us that their support staff told them about the inspections before inspectors arrived at their homes.

Residents spoke of their experience during the last inspection of their service. One resident told us, "It was grand, very good. Very relaxed. It went well anyway and relaxed environment."

In one forum, staff told us that HIQA is discussed as part of the monthly advocacy meeting.

We also heard about some of the negative feelings that residents experience when there is an inspection in their home. Staff supporting residents in one focus group acknowledged the stress that staff experience before and during an inspection of the service, telling us that residents pick up on staff members stress when there is a HIQA inspection and as a result, there is a noticeable change in residents' behaviour.

Staff representing a group of residents told how residents are less anxious when they have been informed that there is going to be an announced inspection and they have time to get used to the idea that an inspector will be in their home. These staff members also noted that the more often inspections take place in the residents' homes, the more used to the process everyone gets and this eases anxieties and leads to a much more relaxed environment on the day of inspection.

One resident told us that they felt the inspection was a frustrating experience for them, but that it was nothing against HIQA, but more so about them disagreeing with some things.

"Couple of things I disagreed with. Felt like, I don't know, felt frustrating. Nothing against (HIQA)."

Their frustration appeared to be in relation to conducting risk assessments. "Risk assessments for chopping, prove on a piece of paper, I can see the point in doing them if something happened I can see the sense."

We heard of a resident's delight that the inspection of their service went well, telling us "We actually passed!"

Some residents were aware that they could read the inspection reports online but commented that the format may not be accessible to all residents across all services. Some residents said staff would help them read the report, or would share the reports with them.

"Staff would help us read them."

"Yeah, the staff talk to us about the report."

However, some residents said that they did not see the inspection report at all, with one resident commenting, "I don't think we are allowed."

When asked how one group of residents found the inspection process, one resident responded:

“I love it when they come back and check everything is great,
at least we know they do a good job”.

Some residents were keen to tell us that they had their eye on an inspector role.

“It’s perfect. I’d take that job.”

3.5 People who are important to me

Residents spoke with us about the people who are important in their lives. They told us that their family, friends and the staff who support them all play an important role in their lives. Due to the COVID-19 pandemic and the challenges that this has brought to the lives of residents, the staff supporting residents have played an even greater role in their lives over the past year, with residents not being able to see family and friends in person, as much as they may have done previously. At the time we met with residents, visits from family were allowed again due to restrictions being lifted.

Family and friends

“My family are the most important people in my life.”

Many residents told us that they rely on their families for support. It was evident that residents found it very difficult not being able to see family during the various restrictions that were in place as a result of COVID-19. When we asked residents what they missed most during COVID-19, many told us that they missed seeing their families the most.

“Seeing my family and my boyfriend.”

“Hard not seeing family. That was tough.”

We heard how staff supported residents to maintain contact with family and friends through phone calls, video calls and text messages. While some residents were happy with this, others found it difficult and felt it was not the same as seeing their loved ones in person, which upset them greatly. Being able to contact their families by phone was a comfort to many residents during the lockdowns. They told us that lockdowns were lonely for them.

“We couldn’t go home or anything. We couldn’t meet our families. We can go home now.”

“I miss my family and they gave me a phone each day and tell me they are proud of me.”



Some residents had their birthdays during lockdown. One resident who had a milestone birthday, told us that they missed celebrating it with family and friends:

“My 40th...it was extremely frustrating being in lockdown.”

Residents told us about the emotional reunions that they had with their families when restrictions lifted. One resident we spoke with told us:

“Family called to see me in the car park and I actually cried.”

Although services found ways to facilitate residents seeing their families and friends during the pandemic, this too brought about some challenges. Some residents told us that their family and friends do not like calling to see them as much now as they have to sign in, so it is easier to go out to meet them at a different location other than their homes. We heard from some residents how they met their friends and family in the garden of theirs or their family’s homes instead of indoors, during COVID-19.

“I appreciate it has to be done, but some people find it intimidating to sign in.”

“Couldn’t have them in in COVID. Had to go outside.”

Many residents told us about the important role that their friends play in their lives.

“I missed my friends over COVID.”

Residents told us they meet their friends in a number of places, including in the community, their jobs, day services, and training.

Residents told us that they missed their friends when they could not see them during the pandemic. Some residents told us about their friends that they live with and how important they are in their life. Other residents told us of how they missed

seeing their friends from day services, many of which had not resumed at the time we met with residents.

"My friends are here, I love them and they love me."

"I have friends in the day centre, yeah."

We asked residents about whether or not they have privacy within their homes to sit and talk with their family and friends when they come to visit. Some residents told us that when their friends come to visit them, they can chat in their bedrooms so that they can have privacy.

"If we want privacy we can have family in our bedrooms."

"Down to my room."

We heard from other residents that their family can come to visit them in their home now, as they have space.

Staff

"Staff support me to grow in confidence and more independent."

For some residents we spoke with, their support staff played a hugely important role in their lives. One resident told us about the important role that support staff play in helping them to feel safe in light of their medical condition, while still ensuring that the resident's privacy is maintained. They said, "Yeah, they are there to keep me safe. I don't mind so that they can hear me if you have a fall or you had a seizure", referring to the resident leaving their bedroom door slightly open at night.

Residents told us about the different ways that their support staff help them. Some residents who have planning meetings said that staff support them in developing their plans and in setting goals.

Overall, residents spoke warmly about their support staff.

"Nice staff. I am very fond of them."

“Love the staff. They look after you well.”

Residents also told us about other ways that staff support them in their day-to-day lives, such as helping them to complete forms. One resident explained, “If any forms for me to sign, or any forms need to be updated, I could go through it with her.”

One resident spoke about how their staff were going to bring them to the local pub to have a curry for dinner, as this is what they felt like having for their dinner that night. Some residents we spoke with told us how their activities are curtailed due to staff shortages. Residents in one service told us that they like to go out but they can only go when staff are available to take them and that this is not always possible.

“Staff restricted in their time.”

“Not all staff have time.”

We heard about some personal goals that residents have, which staff were supporting them with. One resident had a personal goal to prepare and cook meals, and spoke excitedly about being able to work towards this goal.

We also heard how staff had helped supported residents to be more independent, grow in confidence and do more practical tasks, such as their financial accounts.

However, not all residents we spoke with were involved in their personal planning meetings, or indeed had a personal planning meeting. Equally, some residents did not have access to their personal files, as outlined under the section on My rights.

We heard how residents missed their drivers who would help them access the community. One resident said, “I miss the drivers because one of them retired and we have to go the long way back now.”

During each of the focus group meetings, residents shared examples with us of the people who are important to them and the valuable sources of support and comfort that these people provide to them.

3.6 Impact of COVID-19

"COVID took control of the world."

"I love it here but COVID caused problems."

COVID-19 and the pandemic had a huge impact on the lives of people living in residential care. This included the use of mask wearing and social distancing within their own homes, as well as not being able to see their families, friends and communities for long periods of time.

We spoke with residents about the impact that COVID-19 had on their lives. One resident told us that they "survived. Think we have to live with it." This was reiterated by many.



Residents understood the public health measures and told us that they wore masks to keep themselves safe and that they followed what the Government said.

We heard from residents who had contracted COVID-19 and how this impacted their lives and the lives of those they lived with.

"I was very sick."

"Virus is very bad."

The pandemic did bring with it some positives, with many residents mentioning that access to technology, such as the options for video calls and virtual meetings was a positive. These tools allowed residents to keep in touch with family and friends, and attend some online classes. Some residents told us that they had their own phones which they used to contact their families when they wanted to. However, this could not replace face-to-face contact.

“When I think of technology, Zoom was good to keep in touch but it’s not the same. Not being able to hug was difficult because COVID-19 was around.”

Residents told us about how COVID-19 impacted on their access to peers and the community. Many residents discussed how they could not meet their friends as a result of COVID-19 restrictions. Another resident told us that they missed going on the bus the most and that they found this the hardest thing as a result of COVID-19.



One group of residents we spoke with told us about the work that they had done with their advocacy group about the loss they had experienced in their lives as a result of COVID-19. They told us about losses such as missing relationships with family and friends and staff members, but also spoke of the positive things that came from COVID-19, such as new activities they did at home, including learning to grow flowers and doing courses. This group of residents told us:

“How COVID has affected us...it’s so important, like other people would be experiencing things too and they could learn a great deal about what we have gone through.”

One resident we spoke with told us that they made the decision to move home during the COVID-19 pandemic, so that they could be with their family.

Some residents shared their worry of meeting people who were not vaccinated, as life returned to what it was pre-pandemic.

“COVID...if anyone came to that door, you would feel that you don’t know who is vaccinated and who is not.”

Some residents told us how they decided to continue to do their own grocery shopping during the pandemic, as they enjoyed it. They told us how they followed the guidelines and wore masks to protect themselves. Many residents we spoke with told us that they did not mind wearing the masks at all; however, one resident said that they did not like staff having to wear masks as they found it intimidating.

It is important to note that residents told us that their right to choice was impacted during the COVID-19 pandemic, as a result of the restrictions that were imposed upon them through public health measures. One resident explained to us that when you know you can go out but choose not to, it is not as bad, but when the choice is taken away, like during COVID-19 restrictions when everywhere was closed, that was difficult.

“Different when you choose to stay in the apartment versus when you have to.”

Residents told us about the changes in their lives since they got the COVID-19 vaccine, for example their delight at being able to go out and about again since they got the vaccine. One resident spoke about being able to go out to do their shopping again as a result of the vaccine.

“I couldn’t go on buses or trains until I had my vaccine.”

“Yes, it upset my routine alright. I got my vaccine and I could start going out again.”

“...I feel like I made the right decision to just get on with my life.”

One resident spoke to us about how they struggled to understand why people would not want the vaccine and that for them getting the vaccine felt like the right decision.

4. Conclusion

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.

They told us about the importance of their rights, their home, their community and people who are important to them. Residents also told us about the impact of the COVID-19 pandemic on their lives.

With the pandemic in mind, and to ensure residents were safe, we held virtual meetings with them in 2022. However, these proved challenging due to technological difficulties, a lack of technology in some centres or sometimes issues of multiple residents in one room using one screen.

A key learning for HIQA is to return to face-to-face forums in future to ensure all residents can participate in the meetings and give their feedback without any issues.

In 2022, we will host resident forums again and look forward to meeting more residents and hearing from them.

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

© Health Information and Quality Authority 2022

