Start listening to us

Report on self advocates focus groups

Áras Attracta Swinford
Review Group

July 2016

Following the broadcast of the *Prime Time* programme 'Inside Bungalow 3' by RTE, the Áras Attracta Swinford Review Group was established by the Health Service Executive to undertake an independent review of the quality of care being provided in Áras Attracta. The findings of the Review Group are presented over a series of three reports.

What matters most is an assurance review that sets out the findings of the Review Group in relation to Áras Attracta itself. It includes recommendations relating to Áras Attracta management, actions for the HSE at a national level, and a 'road map' to guide all managers of congregated settings as they move towards decongregation.

Time for action deals with the wider system of service provision for people with a disability, and proposes a range of actions including 55 priority actions that emerged from a national process of consultation with stakeholders involved in disability services and the wider public.

Start listening to us is a documented record of the lived experiences of people with intellectual disability and how they perceive the support they receive.

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Foreword

This report forms part of the Áras Attracta Review Group public consultation and final report on how we can rebuild confidence in our services and improve support for people with intellectual disabilities.

We consulted directly with people with intellectual disabilities who are living in a range of settings, ensuring that their voice is heard.

The content and comments are a documented record of how the people with intellectual disability who participated in the process see the world; it records their lived experiences and their perception of how things are regarding the support they receive.

In places the factual accuracy of their comments may not be absolutely correct – but that is their perception, and it is vitally important that we hear the messages which are communicated powerfully in this paper.

We need to read this report alongside the final report in which we set our response to the earlier consultation paper this year.

We must do everything in our power to ensure that people who depend on others for support are protected from abuse and neglect, and that we strive to ensure the delivery of high quality support that is open and transparent, and that encourages and nurtures talent, capacity, potential and independence. We also must ensure accountability and a system of support that inspires confidence in all of us.

I urge you to read this paper in full and to share it with others. In particular, if you are in a position of authority in your organisation, I would strongly encourage you to ensure that every member of your management and staff team has a copy of this report and that they read it.

Kevin McCoy

Dr Kevin McCoy,

Chairman, Áras Attracta Swinford Review Group.

Acknowledgements

The Áras Attracta Swinford Review Group wish to thank the Self Advocates who participated in the Focus Group meetings.

Special thanks also goes to Fiona Duignan of Inclusion Ireland for her coordination of these meetings and to Sarah Lennon and Áine Ní Aileagain from Inclusion Ireland who facilitated all the meetings.

We also wish to thank the independent scribe, Marie Treacey, who recorded all the meetings.

Thanks also to Seamus Logan, Independent Consultant, who assisted in the planning and production of this report.

Finally, we wish to thank everyone who attended the meetings and spoke out so powerfully and authentically on behalf of everyone with intellectual disability in Ireland.

Áras Attracta Swinford Review Group Members

Dr Kevin McCoy, Child Care and Social Care Consultant, Chair

Deirdre Carroll, Independent Disability Policy Analyst

Ann Judge, Management and Organisation Development Consultant

Dr Bob McCormack, Service Quality Consultant

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Introduction and background

In December 2014, the RTE *Prime Time* programme broadcast an undercover investigation into the care being provided in Bungalow 3 in the Áras Attracta residential campus in Swinford, County Mayo. The programme showed evidence of physical abuse and neglect and a staff culture that seemed to regard this approach as normal or tolerable.

A national scandal ensued and the Health Service Executive (HSE) immediately established an independent Review Group to make recommendations about cultural change, quality of life and a how to reduce the risk of abuse not just in Áras Attracta but in all services for people with an intellectual disability in Ireland.

In August 2015, the Áras Attracta Swinford Review Group (ÁASRG) published a national consultation paper. This was the first stage in a process that led directly to the consultation meetings and sought to ensure that the voices of people with intellectual disability are heard.

1.1 How we conducted this consultation

The ÁASRG met with Inclusion Ireland, a national rights-based advocacy organisation promoting the rights of people with an intellectual disability and their families. It was agreed that the consultation would cover all residential services in each of the nine HSE regions and that this would require thirteen meetings (to allow for the bigger regions). The meetings were planned to start in early October 2015 and it was agreed that Inclusion Ireland staff would facilitate all thirteen sessions which would be organised through letters, phone calls, posters and the use of social media.

It was also agreed that the Inclusion Ireland facilitator would be supported by a professional scribe. It was anticipated that sessions would be oversubscribed but Inclusion Ireland would limit attendance to around ten people per session including people from a variety of settings. Transport costs were included in the plan. Each session was planned to run for up to five hours (including lunch) with the process completing by 30 November 2015. Inclusion Ireland intended that the same person would scribe all sessions and would produce detailed separate reports for each session.

A variety of activities in the sessions was planned in order to maximise participation and to ensure that people with different degrees of disability were included in the sessions and facilitated to respond.

It was also agreed that Inclusion Ireland would try to take those attending to a neutral venue as this would encourage good participation. Only people with intellectual disability from residential services, their supporters (including relatives) and the Inclusion Ireland facilitator and scribe would attend the sessions – in order to minimise any distraction or inhibition.

Participants were to receive expenses payments on the day they attended.

The plan was executed as agreed with only one session postponed and rescheduled. Details of the meetings are listed below.

Table 1.1 Meeting locations and attenders

Location	Male Attenders	Female Attenders	Total
Dublin North	9	4	13
Dublin West	5	4	9
Dublin South	4	3	7
Castlebar	6	5	11
Kilkenny	3	7	10
Wexford	5	2	7
Cork	9	7	16
Killarney	7	1	8
Drogheda	2	3	5
Athlone	3	3	6
Galway	8	8	16
Limerick	4	13	17
Sligo	8	7	15
Totals	73	67	140

The size of this consultation, involving significant time spent with such a large number of people, is in itself remarkable. Most of the 140 people attending were aged over 25, many were aged 40–65, but there was a small number under 30 with a handful aged under 25. Similarly, a minority were aged over 65. One person had an electronic board to communicate with as his speech was difficult to understand; (he attended without it).

Some had physical disabilities or hearing or visual disabilities, and a small number required considerable assistance to be able to communicate their views. A small number who attended did not speak.

At all of the meetings most of the participants contributed without the assistance of their support staff, although in nearly all meetings some support staff did stay at the request of those present. The facilitators at all times left the decision with the person with intellectual disability in this regard. One older person used an Ipad to write down what he wanted to say and his support staff communicated it to the group. However, in general most people were well able to speak up for themselves and at all times had lots to say at the meetings.

The notes and points below are summarised from these thirteen meetings without identifying individual speakers. Other details such as placenames or identifying information are omitted to protect confidentiality. Individual quotes are in green with separate lines for separate quotes.

The questions discussed are those used in the 'easy read' version of the consultation. The first two questions have been combined because the discussion addressed both questions simultaneously. Two questions were not addressed during the consultations, as they were specifically addressed to organisations, managers or staff.

1.2 Reactions to the RTE programme

A number of meetings began with a discussion around people's reactions to the RTE *Prime Time* programme and below are some of the initial feelings expressed:

> 'RTE did the right thing exposing such behaviours.'
>
> 'No staff in any centre around Ireland should do that.'
>
> 'They are human beings like us all; they shouldn't be treated or abused like that.'
>
> 'I cannot forget what I saw in that programme.'
>
> 'It shouldn't have happened.'

2 The questions discussed

2.1 What laws need to be changed and how can this be done?

There was awareness in some groups of legislation such as the *Disability Act 2005* or the *Citizens Information Act 2007*, but others seemed to be unsure of the difference between legislation and policy or were unaware of specific policies – for example, the *Time to move on* report.[1] On receiving some information, the people present had a lot to say.

> 'There should to be more places to go around, more money needs to be put into these services.'

One group was very aware of legislative and political practices such as voting, the Senate, and the Dáil. They felt their futures were being decided by TDs and senators without any input from people with disabilities, but felt powerless to do anything about it.

> 'Politicians don't do much for you. There are no wheelchair users in the Dáil.'

One of the people present at this meeting argued 'we want action, not more reports and strategies'.

Another group were aware of various legislative frameworks and policies and so were quite knowledgeable about relevant issues. However, they believed that not enough information is filtering down to them from the Health Service Executive (HSE), the Health Information and Quality Authority (HIQA) and the service providers.

> 'We don't know what is in the documents, how can we make decisions, we need more information on legislative matters.'

One person brought up the issue of funding for holidays and the fact that the Government had taken the funding relating to his service away and they could no longer go on holiday. His service was only able to go on day trips as:

> 'There was no money left in the kitty to pay for holidays. It's not fair to us.'

Some people had heard of the *Value for money* report,[2] and felt that:

> 'It means we have the choice of who and how we are supported by services, we have control of the money and spend it as we see fit.'

People were happy to hear that smaller numbers living in groups of fewer than ten was the way forward.

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[1] Health Service Executive, 2011. *Time to move on from congregated settings: a strategy for community inclusion.*

[2] Department of Health, 2012. *Value for money and policy review of disability services in Ireland.*

> 'There should be smaller groups. There are 11 in my house and only three staff from 9 to 9 in the day; then the night staff come in. We need more staff, it needs more money. The HSE should put more money into this type of stuff. There are a lot of empty houses out there – why don't the HSE buy them and rent them out to those who need them?'

One female participant seemed to be particularly worried about 2018 when her unit would be closing down; she kept asking when it would be closing.

> 'People should be consulted, talked to, they shouldn't be moved all around without agreement.'

Some of the people at another meeting believed they had seen improvements in day services, with regular trips out during the day such as to the cinema, swimming, mountain climbing and walks.

Another group believed that legislative changes should be implemented in consultation with them and their wishes.

> 'We could work in partnership with staff; consult us, listen to us, show that you consider our ideas, our feelings.'

With regard to the *New directions* review,[3] a number of issues were raised about day services and problems associated with transport, and lack of staff.

> 'Day services are great, but if you live in a rural area transport is a big problem. I can only use public transport two days a week as that's all that is available in my area. The Government have not got a clue about living in rural Ireland.'

A recent programme on TV3 was mentioned where a number of high profile rugby players highlighted access problems for wheelchair users.

> 'If we had more support in the community we could learn to get around ourselves. We can learn how and where to go for our day services but the transport system is not fully functioning; so even if we did know how to get there, we cannot.'

However, the lack of staff was an issue that was raised again and again in these sessions.

> 'If I want to go out to a football match, I cannot because there are only two staff in my house and they need to look after someone who is in a wheelchair – so I cannot go as there are no staff available to go with me.'

> 'It is no use having policies if there is not enough funding; proper funding is the key.'

Not everyone was negative about law and policy. One person reported that she had her own computer and orders her clothes online that way and was happy with this arrangement. She goes out daily for various activities such as bowling, the cinema and liked to check her activities online before she headed out to them.

> 'We all have our things that we like, it's only right that we should be able to do what we choose to do; we feel lucky that we can, but we should be able to. Swimming, walking, work – it's our choice.'

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[3] Health Service Executive, 2012. *New directions: review of HSE day services and implementation plan 2012–2016 – personal support service for adults with disabilities.*

Summary: **What laws need to be changed and how can this be done?**

People were sceptical about how the law can improve things for them. They had a low knowledge of law and policy but wanted action to make things better.

There was a view that promoting real life choices for them would cost more money.

Some were concerned about the move to smaller group living but this was welcomed by most people, who simply wanted things to move faster.

Transport and day support were highlighted by many, but the overwhelming theme was the need to consult and involve people with an intellectual disability about the decisions that affect their lives.

2.2 What policies need to change and how can plans be made in a better way?

Some groups had mixed levels of knowledge regarding planning and policy.

> ‘Keeping everything top secret – information should be shared especially if it concerns us as people.’
>
> ‘Everyone should be treated equally and given the information necessary for them to make informed choices.’
>
> ‘There is nothing on the walls of residential units, so it’s not easy to know what policies are in place. You have to ask to get the information. It should be more readily accessible and available to us.’

Many people didn’t know of the plan for large residential units to be closed by 2018, but believed it was a good idea.

> ‘Those who are able to live alone should do so.’
>
> ‘More staff are necessary; there isn’t enough staff on the ground, especially for severely disabled people.’
>
> ‘Staff don’t have time to check up on you as they are busy with reports, paperwork – it takes all their time.’
>
> ‘More one-to-one interaction between staff and us, it’s just not happening.’

One person believed that the people in the services should write the policies, enabling them to design their own service around themselves.

> ‘We should train staff; there is a lot of talent out there, start using it.’
>
> ‘There should be more staff so that one-to-one services can be available for us.’

Another group also believed that they should be able to be involved with planning new policies which would help to improve things all round.

> ‘If we were involved it would help people to feel safe, to have confidence, that they will get a good service.’
>
> ‘Maybe if we were involved there would be action, not just words.’
>
> ‘We learn quickly if we are given a chance to do things ourselves, so why not let us help with policy planning?’

> 'We could help to plan for people to have a more independent life.'

One of the supporters at this meeting spoke about her son who also has a physical disability but has availed of a personalised funding package. He has his own apartment, his own personal assistant and the funding comes directly to him to pay for the support/services he needs. She believes that more people need to be made aware of this system and should lobby for the right to have this type of funding available to them also.

Summary: What policies need to change and how can plans be made in a better way?

Information was again highlighted – with the example of putting posters on walls.

The issue of staff having time for social interaction as opposed to paperwork was also mentioned by many, as was their own involvement in policy-making and training.

A few people knew about personalised budgets and the advantages of being in control.

2.3 What should leaders do to improve the way planning happens?

Most groups believed that they should be consulted about new policies and plans. They believe this would aid the implementation of current policies as well as newer policies.

> 'I don't want the service providers telling me what to do. I am an adult and want more choice.'
>
> 'Service providers won't tell me how much money I have in my own bank account. I should know, it's my account. It's (our) money but we have to sign for it, I want control of my own money. Out of my allowance each week I have very little left for myself after paying rent, etc.'

Two people who are smokers were unhappy about being given 'pocket money'.

> 'I'm a middle aged man, I should have my own money. I've been told that I'm not 'entitled to it' by staff. Money goes into my bank account each week, staff take out the money – it's not right.'

One of the female participants commented:

> 'They are not in the 21st century, they think we are still in the 19th century. I have had to fight for everything I have got, I have been fighting for the last 13 years, and I'm tired fighting.'
>
> 'Some staff think it's their job to abuse you just because you have an intellectual disability.'

At one meeting, the Health Information and Quality Authority (HIQA) was discussed in this regard. The group as a whole had heard of HIQA and believed that it was a good idea to have them overseeing the process of ensuring things were done properly.

> 'I have met people from HIQA, they called to my house. I didn't mind people coming to my house.'

Different labels such as 'client', 'service user', 'resident' and 'customer' were discussed. One of the people present had strong feelings about being called a 'client':

> 'Client is a disgusting word, you can just call me Tom Dick or Harry. I would rather be called by my name.'

A number of the participants at one meeting had been on the receiving end of some bad treatment.

> 'I had a very bad experience with the staff nurses in one place, I was mentally ill when I arrived. They dragged me to the day room to take tablets, gave me injections. They took my SIM card out of my phone and threw it in the bin. My father, when they told him this, asked them why they did it, and they claimed it was because I didn't want to go to the day room.'

One person believed that it wasn't worthwhile to complain as it 'falls on deaf ears'.

> 'Why do staff tell us what to do, we ourselves know what's best for us, what we need, what does and does not work. Where's the respect in that?'

> 'When I was in that service we were forced to wear gowns, it was degrading, and undignified but we had to accept it. Now at least we can wear our own clothes.'

> 'It's a wonder how people got away with it. They are still getting away with it – we should stand up and fight.'

One of the people at this meeting mentioned that her residential unit had received a letter complaining that the people there were not clean and tidy, and told to ensure that 'everyone is clean and tidy, that they wash before going out on trips'.

It transpired that a local pub/restaurant had complained about the group's hygiene. She felt that they were being discriminated against and that 'we always go out clean and tidy, they won't serve us there any more.' She was upset and her father was very angry about this treatment and felt that the heat in the venue was excessive and that 'even waitresses would be smelly in the heat of that place.' However it is 'the only pub for miles'.

This type of situation, she feels, shows the lack of respect and undignified treatment that people are subjected to and that it has to change. The group were asked what could they have done about the situation and it appeared no one took action, or wrote back or realised that the venue could have been taken to court.

Summary: What should leaders do to improve the way planning happens?

Being in control and having choice were key issues, with access to and control of money being a strong theme.

People were aware of the role of HIQA in promoting excellence and preventing abuse, but some examples were given of abusive behaviour by some staff.

Discrimination within wider society was also experienced with one very powerful example highlighted.

2.4 What can services do to make sure people are treated with dignity and respect?

A variety of views were expressed about what should happen across the range of congregated settings. Many groups voiced their strong feelings about the events in Áras Attracta.

> 'How would those staff feel if the tables were turned on them?'

They all wanted to see justice done.

One group believed there should be more staff on duty to ensure such treatment cannot happen. Additionally this group believed that they should have more access to their files.

> 'I should have my files in my possession myself. If files are to be viewed by a specialist for example, then the person should be consulted for my permission to do so.'

One person cited an incident she witnessed while in respite, where a fellow resident was told they couldn't use the Post Office and the Bank; she advised the person that of course they could use both.

Two of the people present did manage their own money and had control, which they were happy about.

Another person believed that her family have too much say in her affairs and that they focus on her disability, despite the fact that she manages herself very well. Support staff were there to help her and she believed the family should let her get on with it.

> 'Not all staff help with managing money, sometimes staff take the money out; it's not right, we should be allowed do this.'

It is only through budgeting and managing their own money that they believe they can learn how to do this efficiently and effectively. They want to be trusted to do so.

> 'Support people to manage their money, help them manage their own money.'

The issue of privacy was raised and many of the people confirmed that they have their own rooms; some had a key, some had not.

> 'My own space, my own room, it's very important to me, all my things are in my room. I would not like a person coming into my room, if they did I would tell the nurse; she would help me.'

But not everyone had this outlook.

> 'People are coming in and out all the time, we don't know who they are and we aren't told.'

Another group felt that in order to be treated with respect then respect has to be shown to both parties.

> 'If staff go on holiday with us they should socialise with us, not sit together at other tables, it is disrespectful.'
>
> 'There should be more male carers.'
>
> 'We have no privacy, HIQA took away our privacy.'

Another group believed that staff in their service should ‘speak properly to people’.

> ‘There should be more funding for proper courses for staff so that they are aware of disability and how it affects those of us living with the condition.’

The flavour of the comments made at one group is outlined below:

> ‘Listen to us, we have a voice, we wish to use it and be heard. I like continuity; when staff changes, its upsets me.’

The people at another meeting had many good things to say about their support staff and how they were treated. However they did feel that the staff should listen to them more.

> ‘Why do staff tell me what to do? I’m a grown man. I don’t need anyone telling me what to do. If I need help I’ll ask.’

The issue of making a complaint was raised and few people seemed to know about the National Confidential Recipient. When this became clear at a meeting, her details were distributed to the group.

One person was not keen on going out very much but, because of a lack of staff in the facility during the day, he was forced to go out every day and this he felt was not treating him respectfully according to his own wishes. He would like his own personal assistant and to live independently according to his own wishes and needs.

Another person who no longer lived in a residential unit, and who now had his own apartment, stated that he had been mistreated.

> ‘They locked me in my room, it was not a nice place, and the staff were not nice to me.’

This should not have happened, he believed, and he was happy now that he had his own apartment and that he was being treated with dignity and respect. He felt this should be afforded to all people regardless of their specific needs. The support should be there for them, he believed.

In relation to dignity and respect, some groups discussed the role of visitors and relationships (boyfriends/girlfriends). One group were happy to have any visitors, even other people’s visitors, they said.

> ‘We stay in touch with our families, I go home at the weekends, to my mother and brother. I like going home; it’s different to the house but I like both.’

One of the people had a boyfriend and she sees him one evening per week.

In this meeting, the topic of death was mentioned and a discussion ensued about how sad it made them feel.

One final group suggested:

> ‘Speak to us, get to know us.’

> ‘It’s more powerful to hear from me about me, not from another staff member.’

Summary: What can services do to make sure people are treated with dignity and respect?

Very strong feelings were shared about what happened in Áras Attracta Swinford.

Access to files and records was also highlighted in the context of having control and being able to do ordinary things with good support.

Privacy and respect for personal space were important themes as was being able to complain or having access to external appeal such as the National Confidential Recipient.

The overwhelming theme was really about equality and being treated with the respect and dignity that any citizen would expect.

2.5 When a person has behaviours that challenge, what support do they need?

A typical view was that people with behavioural issues should be treated with dignity and respect by staff who have the relevant experience and professionalism necessary to manage their care. It was not acceptable that they should be treated less respectfully.

> ‘Staff calling us “muppets” is not acceptable, but the staff member still does it despite being cautioned about it.’
>
> ‘Those who are challenging should be cared for by professionals; they can’t help their behaviours – they are like us. Staff need to be well trained and professionally experienced to be able to deal with such behaviour.’

A further group believed that while the *Prime Time* programme was a good thing, they should not have to rely on that type of programme for changes and improvements in their services.

> ‘Some people’s families move away and they are left without any family member to look after their needs; they can be abused. Staff need to be trained professionally to ensure that their support and care is suitable for the needs of the person. It’s not a “one size fits all” system.’
>
> ‘Staff shouldn’t get annoyed. They shouldn’t get annoyed if I come back early, or late from an appointment. They are there to support me, not get annoyed with me.’
>
> ‘Staff numbers need to be adequate to deal with the different types of care that is necessary in individual units, suited to the person and their care and support needs.’

The view that a lack of adequate staff (owing to cutbacks) was leading to problems dealing with people who exhibit challenging behaviours was a prevalent one.

> ‘If there were enough staff on duty then such issues may not happen so often.’
>
> ‘If staff are happy in their job, then when such issues arise they can deal with them professionally and humanely without resorting to violent or cruel acts’.

> 'HIQA are there to help with such matters – if they were doing their job properly such things wouldn't happen; more inspections are needed.'
>
> 'Residents often hurt other residents, it's not just the staff.'

One group stated that they believed that what had occurred in Áras Attracta is probably more widespread than is known. In another group, the questioning around this issue was along the lines of being safe and how people would deal with a safety issue and what they would do about it. If they needed help they would call the nurses – they felt happy and confident to do so, in the knowledge that she/he would help them to sort it out.

> 'Sometimes there are fights but that's normal; the staff sort it out for us and we are happy.'
>
> 'They sometimes shout at you; I don't like it, I shout back.'
>
> 'I wouldn't like to live here all my life; I want to move out.'

One group believed that people with behaviours that challenge may well be behaving this way in an attempt to get help or attention. Lack of or shortage of staff means people, particularly those who need extra help, are often left without that help and this can lead to frustration and cause bad behaviour or behaviour which can be seen as threatening or disruptive. However, they believe that the type of treatment that occurred in Áras Attracta cannot be condoned or excused, whatever the behavioural challenges presented to staff.

> 'Staff who are qualified and experienced need to be available to deal with such behaviour.'
>
> 'If there were more staff available at all times these types of events may not happen, or at least not happen very often.'
>
> 'Sometimes there can be personality clashes with people.'
>
> 'Staff should be given inductions, trial periods to see if they are suitable to the job, whether they can look after the people in the place who have different needs and may need specialised care. If they aren't, they shouldn't be there.'
>
> 'If staff are not looking after the people who need it I wouldn't let them away with it, I would name names, tell police what was happening.'

One of the people felt that people's basic human rights should be upheld at all times regardless of what behaviours they exhibit. Staff should be professionally trained and experienced to deal with such challenges.

Summary: When a person has behaviour that challenges, what support do they need?

People were not prepared to accept that behavioural issues meant that a person did not deserve respect. They wanted professional behaviour from well-trained staff.

They highlighted vulnerability associated with isolation and again raised a question about inadequate staffing levels in these care settings.

HIQA was seen a major source of protection as were nurses, but there was a sense that abuse is more widespread than is known and that some behaviour is a form of communication.

2.6 Does the culture in services need to change?

Almost all groups believed that their needs and wishes should be taken into consideration but felt that some staff do not take them seriously and treat them like children on occasions. Promises are made (for example, to go out for an afternoon), but when the day comes they sometimes do not go as 'there are not enough staff available'.

> 'Services are supposed to be for our support, not what the service provider needs or wants.'
>
> 'There should be one-to-one meetings to discuss things; staff cutbacks mean they don't happen so nothing changes or improves.'
>
> 'They have the power over us, they are the staff.'

One had recently lost one of his friends from another unit and was struggling to deal with his feelings about it. It was suggested that training should be set up for this.

Another group believed that a better culture now exists where they live.

> 'There is privacy where I live now, they are respectful of my privacy.'

Others were less positive.

> 'Age appropriate treatment is needed: we are not children, we are adults, do not call us baby names like "pet", "love", "honey"; it's degrading.'
>
> 'Some staff are too serious, take their duties too far; when they are too strict they say "it's my duty of care to be like this" – not true.'
>
> 'New staff should be shown around the home by us; it's our home.'

Another group also believed that they needed to be more involved in how their service providers run their services for them.

> 'Regular meetings in our homes/residences would help – to update, to see what's working and what isn't working – this would help a lot.'
>
> 'We could support other people to do things, advocacy groups etc.'
>
> 'We should be included in the staff meetings and management meetings; they are discussing us so we should know what's happening.'

People believe that their involvement would help to change the culture that prevails among staff in their residential settings. They believe that staff are very often busy with paperwork which means that they don't have the time.

> 'We can help those who cannot do things for themselves so the staff could be available for other things.'
>
> 'We should be able to introduce new people to the houses, meet new staff and help them settle in.'
>
> 'I want to be on an interview panel so I can meet the people who will be working with me before I meet them at my home/residence. Where I work there are four people who are going to be trained on interview panels – they will help to choose our staff; they know better what we need.'

Many groups had a lot to say about quality improvement approaches and HIQA: some good, some not so good.

> ‘They make sure we are safe, that the house is clean, that the staff are good staff.’
>
> ‘Staff get stressed; they are treated badly by HIQA.’
>
> ‘They check that staff are doing their job correctly, not like what happened in Swinford.’
>
> ‘Safety is important – fire drills, fire exits; they are needed and HIQA check these.’
>
> ‘They are suited types, very official looking; they make you feel bad. We should be inspecting the services, not them.’
>
> ‘They should introduce themselves to us, so we won’t be nervous.

Some groups were aware of developments like Service User Forums (SUFs) which are in place in other places and feel that more of these forums should be set up.

Summary: Does the culture in services need to change?

A significant theme concerned regular, respectful consultation aimed at empowering people. However, there was continuing scepticism about the impact of cuts to services. People wanted to be more involved in the management of their services so that staff resources were free to do other things and SUFs were highlighted. HIQA was again highlighted both positively and negatively.

2.7 What can be done to make sure things are improving all the time?

Most meetings focused on HIQA. One person said that HIQA visited her residence and stayed for dinner. She was able to ‘speak up without help’ at that dinner and they ‘wrote everything down’ that she had said.

When questioned regarding their awareness of what HIQA is there to do, groups said they were there to make sure people were safe, properly looked after and treated respectfully by staff. They were generally not afraid of HIQA employees and said they would ‘speak out’ if necessary.

> ‘Our house was cleaned before they came; we have fire checks now and we know where the fire exits are – that’s important.’
>
> ‘They asked to see my room, I said “yes” with a support staff member with me. They also looked at my personal outcomes book, and she (support staff) had lots of paperwork to do afterwards.’

One person who lives independently with a personal assistant did not agree with some of HIQA’s rules.

> ‘Exit signs, files, reports, worrying about these things – it’s not how we want to live.’

Others had a number of negative points to make about the role of HIQA and the effect on their day-to-day lives.

> 'We don't see enough of our managers. They are doing work for HIQA, but they want to spend more time with us.'

In contrast, another person was happy with HIQA's changes to his living space. Thanks to HIQA, a sitting room was made for him to enable him to have his friends over and do what he wishes to do.

However, there was a wide variety of views.

> 'Who do they talk to in these places. They only want paperwork, they didn't want to speak to us – it was all paper, paper, paper.'

> 'They asked me questions, I felt safe talking to them.'

> 'We cleaned the house top to bottom but they still weren't happy.'

> 'Staff should be doing things and going places with us, they used to before HIQA. Before HIQA, we went out more.'

> 'People are coming and going all the time, at weekends, doing paperwork, there is not a lot happening, and the weekend is gone, I would change that. They used to help me with my medication or take me shopping; they don't any more since HIQA.'

> 'HIQA are not in our shoes, they don't have to live like we do. We ourselves would make good inspectors, we know what is a good service and what isn't.'

However, as another person put it;

> 'HIQA are there for a good reason. Áras Attracta is why it came about but they didn't pick up on the abuse originally, they didn't do their job, they gave them a clean bill of health the first time they visited.'

One meeting suggested that no advance notice should be given about visits as it gives staff time to sort out any problems in advance. Day services mean most people are out and about when HIQA visit so very few people are there to talk to about what kind of service they are receiving. They believed they should visit when it's busy, talk to clients, family members and other visitors. HIQA, they believed, are following their own rules and regulations, and are missing the point. They also believed that the background of the inspectors is important, and that they themselves would make good inspectors.

Some people mentioned the need for a register to be set up to take note of and log abusive care workers. They felt that such people should never 'work around people with a disability again.'

One group discussed how they did not get any feedback on what HIQA had reported, or about what would happen next. They knew that HIQA sent a report and they believed they should be told what was in the report. However, one person advised that her service had made the HIQA report accessible to her to read. Another person then said she got feedback from her psychologist.

Another group believed that too many nurses were being replaced with care workers. It was argued that they, the residents, should have a say in who is being employed and that they are not being consulted in this regard.

Summary: What can be done to make sure things are improving all the time?

Most groups focused on HIQA in their responses and they seemed to have a good understanding of their role. Tensions were referred to between the need for health and safety and the need for 'homeliness'. A range of views were expressed, positive and negative, and the role of people with intellectual disability as inspectors was again highlighted.

2.8 What can be done to stop abuse or neglect?

At one meeting it was agreed that being able to make a complaint or highlight a particular issue without fear of some sort of 'backlash' or ill treatment was very important. However, they pointed out that they were reluctant to make complaints about particular staff members as they were 'afraid they themselves would get into trouble'. Because of this, almost no-one had ever complained.

Another person said that:

> 'The complaints process doesn't work, it needs to be more accessible as people who cannot speak are being abused, not just by staff, but by other people.'

One group believed that bullying goes on a lot and that they need a complaints process designed by themselves to combat this.

> 'There should be a whistle-blowing system in place to enable us to complain anonymously.'

One person stated that:

> 'I complained in the past about problems, but it's not taken seriously. If something happens to upset someone and they make a complaint, who is the manager going to believe, to see as more believable, the staff member or us? We are treated like children.'

Another person told the cleaners at her service about abuse and they came to her aid and complained to the manager of her service on her behalf.

Some groups believed that the person they should complain to should be an independent advocate, outside of their service.

> 'We need someone strong who is above everyone else, like a solicitor or something.'

> 'More advocates are needed to help us complain but it's very hard to talk about this stuff.'

> 'It's important that it's confidential, people might be offended if you complain about them.'

> 'I would speak to a family member or a trusted member of staff if I wanted to make a complaint, I would feel safe to do so.'

The National Confidential Recipient was again discussed in this regard and again, the group were not aware of her details.

> 'The problem is that's only one person, so how can it help everyone?'

One of the people present said that she had her 'hands tied behind my back, I was given injections, and my stuff was taken'. She said this had happened only a few weeks previously.

Another group believed that more staff are needed to prevent and identify neglect. Cutbacks, they believed, was why issues of neglect were being highlighted by HIQA inspections. In most cases, people believed it was not intentional on the part of staff, but the lack of staff plus a rise in paperwork meant that the staff who are on duty are not giving people the level of care and attention they need. They also believed that it would be important that their identity is protected in the complaints process to ensure that they do not become victimised.

Many people at the meetings believed that policies and procedures were in place in their service, but felt that often they needed to be reminded of how to go about using these policies if they needed too. They felt that they needed to be given more information.

Summary: What can be done to stop abuse or neglect?

The complaints process was highlighted by many groups as was the potential role of advocates in dealing with complaints. Bullying by fellow residents was mentioned as requiring attention. Many people highlighted the need for confidentiality and the issue of staff cutbacks was again mentioned as a reason for why abuse might be occurring.

2.9 What would help people with intellectual disability to live well?

Choosing their own medical care was felt to be a key aspect of their healthcare, and of ensuring better outcomes for them. A number of groups felt that they should, where possible, self-medicate – they know their needs and their medications and so could oversee their own medical needs with support.

> 'I can self-medicate now, but it wasn't always the case – the office used to do it.'
>
> 'If my own doctor is not available I should be able to choose another doctor myself, not the doctor chosen by my service provider. I want to be able to choose whether I have a female or male doctor to call on me to provide my care.'

One person commented that often doctors won't take patients with intellectual disabilities, citing being 'too full' or 'we don't take medical cards'. Another person, who is in a wheelchair, cannot access his doctor's house as it has no wheelchair ramp – so the doctor has to come outside to him and consult with him in his car.

Some reported satisfaction with their health support – for example, their doctor came to see them and their medication and their treatment were supported to their satisfaction.

One group, in common with many others, wished to be able to self-medicate and choose their own medical doctor. They feel they are capable and can ask for a little support if they need it.

> 'I am a diabetic, I need a bit of support, but I'd rather do it myself.'
>
> 'It's better to go out to the doctor – you meet more people.'
>
> 'I might need someone to remind me to take my medications, or give me an injection, or to use my inhaler, – I have asthma.'

A discussion about personal plans and health ensued at one meeting. Many had their own Personal Care Plan in their room; some were not aware of it but were happy it was being taken care of for them. Another group echoed the points about more choice around administering medication and who they visit such as doctors, psychologists and associated staff that look after their different needs.

> 'I do have my own doctor but they talk to the staff not to me.'
>
> 'Things should be face to face, people should be told, not someone else, like my sister.'
>
> 'I have a medical card but I cannot choose my own doctor. Why not? We should be able to.

One person pointed out: 'There is no doctor in our town'.

The issue of being changed from one medication to another medication and the issue of side-effects was discussed.

> 'I asked my psychologist about side-effects – he gave me information on it – I wanted to know why it had been changed.'

Another person advised that he talks to staff who advise him on his medication.

> 'Staff will always tell me if I need to go on different medication and why.'

The issue of contraception and sexual health was raised at this point as one of the people present had recently become engaged. He believed it was important for him and his fiancée to have information on sexual health. Another person related how (after having sex) she was put on the contraceptive pill without her knowledge or consent.

At one meeting, mobile phones were felt to be important as they allowed people to keep in touch with various healthcare staff and/or arrange to meet them when they were out and about during the day.

At another meeting, everyone appeared to have medical cards and they felt happy that they had this 'security' although prescription charges and rising medical costs impacted on their medical services. They were happy to go to their medical appointments with support when necessary.

> 'I go with staff support to the doctor as, when he is talking, I often cannot understand what he is saying.'

Some of the men at one meeting were more in favour of making their own decisions regarding their medical care and wanted to go to the doctor alone rather than be accompanied by a staff member. They felt that it was their private business and strictly between them and the doctor attending them.

Summary: What would help people with intellectual disability to live well?

Most of the groups focused on choice, self-medicating and being given better information, including about the effects of medication. The theme of personalised care was clear with people asking for equality with every other citizen.

2.10 What can be done to make the management of services better?

In answering this, some groups concentrated on the need to live in smaller groups, perhaps with friends. Some people living in larger groups believed the groups were too large.

> 'We need to live near others, near towns, shops, and other services.'

One person highlighted that he was not allowed to have his own door key (to a home he is paying rent to live in) and sometimes experienced being left outside in bad weather until a staff member let him in.

> 'I feel safe when I have my own key, I can lock my room, get in and out of my home – its normal after all to have a key.'

Another person highlighted the fact that she was not allowed out after 8pm in the evening, which she believed was unfair. Another person was not allowed to lock her own room despite wanting privacy. She had a boyfriend but was not allowed to see him at a time of her choosing.

In another part of the country, a group said they would like to have more say in how their residences and homes are being run. They believe rules and regulations take precedence over their needs.

> 'It's my room, my home. I don't want my room being inspected to see if it's tidy. If I want to have a messy room, I should be able to: I am an adult. Everything has to be spick-and-span in our house – it's my home and I should be able to have my room the way I want it, with my stuff how I want it.'

Many groups felt they could not choose who they live with and that this does not work. They felt a lot depended on personality, mood, privacy issues, different wants and needs, and a range of other factors.

> 'If people were supported to live independently in the community, then management of residential units and services wouldn't be an issue.'

Some people wanted to 'do normal little things that others do'.

> 'I live in a house with seven people, there are only two baths, two showers, and two toilets. It's not enough for all of us in a house together. There is a big side garden which could be used to build on some extra facilities to make things better.'

Another issue that came was what people did during the day. One person, who used to work in a bookshop and also in sheltered workshops, believes there are not enough work opportunities now.

> 'Lack of day services means we don't go out much at all.'

Money management was raised. Sadly one of the men said:

> 'I never bought anything for anybody in my life.'

One of the younger people didn't like having money on his person, and needed help buying clothes.

> 'I don't know what to buy apart from cola, chocolate bars.'

Another person commented:

> 'I love shopping – I got three dresses for Christmas.'

Some comments concerned CCTV.

> 'They want to put CCTV cameras in to keep an eye on us, but it's invading our privacy. You can understand why they would want to do it but you have to show respect for us too.'

Having input into the management of their services was also mentioned. It was felt this would be beneficial to both residents and staff. They also felt that being safe, having privacy, having support and the choice of who/how many people they live with is important and would help with the management of their residential services.

> 'Some of the places are big old buildings that were once something else. These aren't suitable to house people with intellectual disabilities – they need to be housed in more suitable places which suit them not the way the service provider wants things.'

People at another meeting believed that having more choices would improve things for them. Such choices related to things such as friendships and relationships, which television shows to watch, as well as being able to manage their own money.

They believed that more training days to discuss these issues would help everyone to manage their shared spaces more effectively.

With this in mind, the facilitator at this meeting asked them if they knew where their money came from and the vast majority of the group had no knowledge of disability allowance or social welfare.

Some groups believed that they should meet with management and staff regularly, at least once a week, to discuss issues and any changes that are happening.

> 'We are never told what's happening, who's visiting, what new people are moving in. We are always last to find out anything.'

> 'There should be more rights groups set up in our services, where we can meet other people and see what's working and what's not. Rights groups give you a voice, get your views across through brainstorming. You get results when you get together as a group.'

One person advised that, in his service, holidays are paid for under a 'programme' which means that they do not have to pay staff for accompanying them on holiday. If funding is cut, people may have to pay more for staff to accompany them.

The issue of marriage and sex was discussed at one meeting. This group strongly believed that marriage and relationships was a human rights issue. If they wished to live with a partner or a friend they should be allowed to and to have intimate relationships. They were aware of the recent Marriage Equality Referendum and feel that it's time for them to be given their rights.

> 'I would like a partner for company. Marriage is a big decision as it's for life, unless you get a divorce.'
>
> 'It's nice to have friends over as well, but when you live with a group you have to make sure they are happy about it as well. If I lived alone I wouldn't have to do that.'

Summary: What can be done to make the management of services better?

The emphasis on this topic was on smaller group living, being able to live as anyone else does with choices, responsibility and independence. Some comments demonstrated how it was often simple things like shopping and money management that were important. Relationships and equality were also discussed with a clear expectation that change needs to happen.

2.11 How can staff recruitment be made better?

A number of groups expressed the view that they should have an input into the staff recruitment process. They also believed that they should be able to play a part in choosing their key worker.

One person reported he had been on interview panels and had provided feedback. He and his fellow house-mates were consulted about the people interviewed, so they were able to form opinions of prospective staff *before* they were employed.

Another person was critical of the role of students.

> 'We get students into our house and they don't know what medication we are on; mistakes can be made. We should be allowed to help them on their rounds, we know a lot and can help them. A lot of us should be allowed to self-medicate – we know our own medicines.'
>
> 'New staff should be trained before they start working with us. Older staff should train the new ones.'
>
> 'We can help with new staff but they need to listen to me about my needs.'

The overall feeling of this group was that if they had a say in recruitment they would feel they had a voice, that they were being listened to – that it's not just about timetables, rosters, service levels, but about *them* and *their needs* being met.

> 'They should be kind. They need to be trustworthy, they should trust you and you should be able to trust them. Ask us what we want more, consult with us, when things are happening we are usually the last to know, to be told. Better staff would not be judgemental or dismissive or get angry when they experience difficult behaviour. If they were more professional in their job it would be better.'

Another group said that more care staff with better qualifications are necessary rather than more managers.

> 'There should be a trial period, then induction; then if the staff member is suitable they are kept on. Sometimes they don't suit the service and the service does not suit them.'

One group emphasised the need for staff to stay on in their services rather than staff continually coming and going.

> 'How can you have a relationship with someone when they up and leave; it's not their fault, but sometimes you feel like it might be your fault.'

> 'Key workers change without any communication by management and it takes a while for people to get to know us and us them; then they are gone.'

One person (who needed sign language support to enable her to communicate) had a new support worker with her who didn't understand her needs – she believed that the support worker should have sign language training.

> 'They should be trained in specific disabilities and how to deal with them effectively.'

Yet another group believed that experienced and professional staff should be in place to assist them with their needs and that staff should listen to them and carry out their wishes.

> 'Get management to advertise for staff, specifically ask for kind, loving, caring staff. We should be able to meet them before they start working with us – then we would know if they were suitable.'

Another group believed they should write up the job descriptions and that gender balance was an issue.

> 'More male staff would be good.'

Summary: How can staff recruitment be made better?

The key theme was for people to have an input into recruitment including writing job descriptions, sitting on interview panels and inducting new staff. Continuity was felt to be important as was disability training and gender balance. Personal attributes were clearly very important to people.

2.12 What are the most important things in the leader's and manager's jobs?

Almost all the meetings believed that in light of the Áras Attracta abuse case, accountability was the key issue and 'consequences for their actions' should follow as a matter of course. Regular meetings and discussions between service providers and residents was felt to be important – to see what was working and what was not on a weekly basis. The importance of appropriate and safe staffing levels was also emphasised – there should be adequate staff numbers on duty at all times to provide a satisfactory service, as and when they need it, day and night.

According to one person, her service provider didn't have a complaints process in place. She believes such a process would be beneficial and ensure that accountability was made a priority for staff who are abusive or carry out their duties in a less than professional manner.

> 'Complaints need to be taken seriously, and if staff see other staff behaving in an unacceptable way they should report that behaviour.'

Another meeting stressed the need for robust accountability practices, including strong disciplinary procedures, to be in place to ensure that events such as the Áras Attracta scandal should never happen again.

> 'Staff should be punished for unkind or abusive treatment, and if a person complains to a manager about a staff member, they shouldn't feel nervous that there will be problems with that staff member as a result of complaining.'
>
> 'Staff should be sacked if they do not do the job they are paid to do.'

One person pointed out that the reason the Áras Attracta situation occurred was because 'people thought they could get away with this, they thought they were above censure.'

> 'It was an abuse of power, they took away the rights of those people. I am surprised that Áras Attracta is still open.'
>
> 'If staff were moved around periodically then they would not become bored with the unit they are based in, they would get to know more people and any problems a person was having with a particular staff member would be resolved amicably'
>
> 'More seriously disabled people don't know about any complaints processes. Their needs need to be prioritised – they should be protected.'

Others noted that changes were already happening.

> 'There are night staff in all units now, but there used to be only night staff in some of them. Each section needs a night manager.'
>
> 'We should be able to go over the heads of management or staff if something is wrong and it is not being sorted out, without fear of any backlash.'
>
> 'HIQA are there for us as well and they need to do a better job in finding out where the problems are in the service and take action against staff and service providers where wrongdoing is discovered.'

One of the groups believed that a robust accountability policy should be in place for all support staff in the event that problems or issues arise.

> 'If they think they can get away with something then they will; they think they are above being punished.'
>
> 'We need more information about how to go about making complaints as this is important.'
>
> 'The management of these institutions should look long and hard at themselves and see how things can be improved for people.'

If staff are unsuitable they shouldn't be working in a support environment, and if a staff member is found to be performing below acceptable standards they should not be allowed to stay working in a service.

As already mentioned above, one group believed there should be a register set up to take note and log abusive care workers to ensure that they do not work in the care system ever again. They should have a record, or a criminal record depending on the circumstances of the abuse. Certainly they should never 'work around people with a disability again'.

Summary: What are the most important things in the leader's and manager's jobs?

Most groups stressed the need for accountability and the need for a robust response when abuse is detected. Complaints processes were also highlighted as was the role of HIQA. A number of people felt that there should be a system to bar people from working in this area if necessary.

2.13 What should be done about education, training and support for staff and residents?

The issue of education and training of their support staff was seen by many as crucial to the quality of their day-to-day support and care. They wanted professionally trained and more experienced staff recruited by the service providers. They wanted to be able to trust their staff to do their best to fulfil their needs, and they wanted to gain the trust of their staff – a two-way relationship.

> 'We want nice, respectful, supportive staff.'
>
> 'We want to work with management to have the staff that we want.'
>
> 'Two-way communication is vital, but it rarely happens.'

One group discussed staff being available to them more regularly to renew and update their personal plans and goals. They felt that low staff numbers affected this and believed that more staff recruitment was necessary to allow better communication.

> 'It's over a year since I had a personal plan update – it should be reviewed at least once a year – it's good to have goals. The staff rosters and timetables should include this; we need to have this opportunity more often.'

A constant stream of new staff is not desirable, they believed. They wanted to have a relationship with their support staff and if the staff were constantly changing it was very difficult to achieve this relationship.

One person believed that 'austerity' had led to a loss of staff, and saving money had taken precedence over quality care.

> 'Money should be spent for the benefit of us, not the service provider. We have no idea where our money goes – there isn't much left for us each week, that's for sure.'

Another group complained that staff were not available to support them. With all the demands on staff (reports, paperwork, cover for absent staff and other issues) they didn't have time to support them fully.

They also believed that with better educated and trained staff, relationships could be improved dramatically.

> 'If we were able to train some of the staff, or shadow them in the day-to-day work, we could help them understand our needs better.'

> 'Some staff are not good, they don't understand us, sometimes they cannot even speak English well. It is not their fault; they are not Irish.'

> 'They need to realise that they should respect us.'

One group felt that staff should not be left to work alone at weekends or late in the evening, and that there should be more staff available at all times to ensure that services are up to standard. They believed that they needed more training in the area of money management, as well as health and safety. They also believed that they could be of help to new staff, showing them around, showing new people around a residence, helping them settle in.

> 'You try to help someone and the staff won't let you. We should be included, but we aren't. We are often told to be quiet.'

> 'We are all equal, so we should be treated the same as everyone else.'

As previously stated, some people felt they could help new staff, show them around the residence/house, train or help to train students/new carers, show them where things were kept or introduce them to other people.

> 'Staff should be trained by us about disability awareness, not by the service provider.'

> 'Management should be available regularly to sit down with us to see how things are going, how they can be improved, iron out any problems.'

In terms of training another group called for better awareness training for new staff, delivered by them.

Summary: What should be done about education, training and support for staff and residents?

In general, people's preferences were about sufficient and adequately trained staff, having sufficient numbers, staff having time to focus on support, continuity and on being allowed to help the staff during training.

2.14 Is there anything else you would like to say to the ÁASRG Review Group?

A number of people at one meeting were also self-advocates involved in advocacy groups and were positive about the good effects of group work in order to bring about changes for the better.

One person described how he was able to meet with the Board of Management (at his location), tell them that he was not happy with some issues, and have changes made.

Another person had previously been part of a rights action group that used to meet every three months and their issues/complaints were then put to a local Board of Management. By meeting regularly they could check if any issues/complaints made at a previous meeting had been sorted out.

This meeting emphasised that getting together as a group is a more effective, safe way of obtaining changes.

> 'More than one voice is better, if there is only one person they can be easily fobbed off.'

Another group believed that overall things are changing for the better but 'slowly, slowly'. However they want to see more change happening more quickly. They think that the best way changes can happen is to open the lines of communication between the people being supported and the service providers. They also believe that having one's own space is important, and being able to decorate that space to one's own taste and needs, even if it's expensive.

> 'Communication with management is vital … so that no one gets upset.'

Some people had overwhelmingly positive comments to make on their day-to-day interaction with staff.

> 'The staff are good to me, they bring me out.'
>
> 'They are nice to us; they have time for us.'
>
> 'They talk to you like to an adult.'
>
> 'All the staff are the same, they are all good – if they weren't in good form I would ask them what's wrong.'
>
> 'I have never seen a bad person; they are all good to me.'
>
> 'Making decisions is a good thing; they help us make decisions.'

Others had concerns…

> 'Stop moving us about, we need to have stability; we need to know who we are living with and choose who we live with.'
>
> 'Transport is an issue in rural communities and it needs to be sorted out.'
>
> 'There needs to be work for us, many of us used to work and want to work but the jobs are not there; and if they are they aren't being paid for their work – who works for nothing in this day and age?'
>
> 'Those who want to live independently should be able to with the right support, such as a PA [personal assistant]. They should be able to look after their own money, bills and that sort of thing.'
>
> 'Be able to initiate changes by complaining to the National Advocacy Service or the National Confidential Recipient – it's the only way we can get any results.'

The issue of age-appropriate language was also raised:

> 'I have seen a lot of positives and great staff but I don't like being 'mammied', being told I'm a good boy or being called "pet", "darling", "love", it's inappropriate language – use age-appropriate language, I'm not a child.'

This group also wanted to be able to go out alone at night and stay out later as one of the people present commented: 'I can't go out alone, but I'd change that, I want to go out alone and do things by myself for myself.'

Another issue which was raised related to having a pet. People reported that they were not allowed have a pet in their home and this they felt was unfair. One person reported that she had a cat and she was delighted, but she lives alone in her own apartment, however, so it wasn't a problem in that instance. People felt that the reason they weren't allowed their own pets was that 'it would create more work for the staff or house-parents if animals were allowed.' They felt that nurturing and caring for a pet would be good for their emotional well-being and happiness.

For another group, the big issue was HIQA and their paperwork. They felt that too much time and energy was being spent in these areas which meant that they were not being supported as they should be.

> 'Give us the choice, to have a partner, to have children, to be safe, it's what we want, our choice, it should be ours to make.'
>
> 'Why do we always have to fight for our rights, for improvements, for change, it shouldn't be this way. It's time for action, no more reports, strategies, reviews, discussion groups. Start listening to us!'

Summary: Is there anything else you would like to say to the ÁASRG Review Group?

Communication was mentioned several times by various groups, particularly between representative groups or self-advocates and management boards. Many positive comments were made about staff but there were also views about too much paternalism and inequality. People generally want action, not another report on a shelf.

3

Conclusion

Much, if not all of what is contained in this report has been written or said before. What is concerning is that these comments are the direct responses of people who, by now, could reasonably have expected that many of these suggested changes would have already happened. It is encouraging that some change is already happening, but the task for the future is to make the good into the commonplace. Most of what is described in this report can be implemented immediately without any cost.

The contents of this report should be taken as an action plan in itself. By restoring confidence, focusing on making things better and committing to a rapid process of change, we can all contribute to ensuring that the risk of abuse and neglect are greatly diminished and that we promote independence and equality for everyone with an intellectual disability.

‘Why do we always have to fight for our rights, for improvements, for change, it shouldn’t be this way. It’s time for action, no more reports, strategies, reviews, discussion groups. Start listening to us!’