



mental welfare
commission for scotland



The views of people with lived experience of mental ill health and related conditions, and their friends and family, on the use of seclusion in psychiatric hospitals

What people tell us

April 2019



Our mission and purpose

Our Mission

To be a leading and independent voice in promoting a society where people with mental illness, learning disabilities, dementia and related conditions are treated fairly, have their rights respected, and have appropriate support to live the life of their choice.

Our Purpose

We protect and promote the human rights of people with mental illness, learning disabilities, dementia and related conditions.

Our Priorities

To achieve our mission and purpose over the next three years we have identified four strategic priorities.

- To challenge and to promote change
- Focus on the most vulnerable
- Increase our impact (in the work that we do)
- Improve our efficiency and effectiveness

Our Activity

- Influencing and empowering
- Visiting individuals
- Monitoring the law
- Investigations and casework
- Information and advice

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April 2019

The following paper reflects the voice, experience and opinions that people with lived experience, and their families/carers, provided for the Commission around their work on the good practice guide *Use of seclusion*. It will inform our work and future reports on this subject but is not, in itself, an expression of the Commission's views on this area.

Groups for people who use services and their family/carers may want to use the stories and opinions gathered, but are requested not to state that they are an expression of the Commission's policy or opinion.

We are very grateful to all people with lived experience and their friends, relatives and/or carers who have contributed their experiences to this project. These are essential to the work we do and our philosophy of involvement and participation.

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What we found out

What we were asking

We asked people if they thought that seclusion was ever an acceptable form of treatment, how they had experienced it, what a place where people experience seclusion should be like and how it might be better handled.

Who we asked

We asked 126 people in 15 groups across Scotland for their opinions and experiences. These were mostly people with lived experience of mental illness but there was a substantial number of friends and family of people with a mental illness, a smaller number of people with dementia and their carers, and carers of people with autism and learning disabilities.

What we found out

We found out that while most people thought that the experience of seclusion is likely to be traumatic (and that the small number of people who had experienced it did find it traumatic) that most people thought it might need to be an option on rare occasions, especially if people are acting violently.

We also found out that many people would prefer seclusion to being forcibly medicated but it was pointed out that the two often go hand in hand and therefore the choice sometimes doesn't really exist.

Some people have a strong desire to be alone when in hospital, and if they could be secluded voluntarily would prefer this to being around other people.

People said that efforts should be made to communicate, de-escalate and provide quiet safe places on the wards in order to avoid the need for seclusion. They did not want anyone to feel that it was being used as a punishment.

People also wanted to be asked their opinion on it, even when they may struggle to communicate, and felt it may be something they might want to put into an advance statement.

People said that in their experience rooms currently provided for seclusion were unpleasant environments that they would not want to be in. They would prefer safe, homely attractive spaces, where they can eat and drink, maybe smoke and have visitors.

They would also like services to have a trauma focussed approach and take that thinking into the provision of seclusion and for the Mental Welfare Commission to look at whether shortage of resources and lack of staff leads to greater use of seclusion and to consider whether the ward environment itself and peoples fear of the ward may lead to greater use of seclusion.

Finally they wanted statistics kept around the use of seclusion and how it changes in different places and over time and for there to be a definition of seclusion that is accepted by all.

Introduction

Over the autumn and winter of 2018 the engagement and participation officer (lived experience) met with user and carer groups across Scotland to find out their views on and experiences of seclusion in hospital.

He met 126 people in:

- Aberdeen: Aberdeen Carers Group – Royal Cornhill
- Angus: Angus Voices - Arbroath
- Angus: Kirrie Connections – Kirriemuir
- Fife: Bipolar Fife – Kirckaldy
- Dundee: Dundee SUN – Dundee
- Glasgow: Restart – Maryhill
- Edinburgh: PASDA - Edinburgh
- Edinburgh: SIM Carers Support Group – Stafford Centre.
- Dumfries: Kaleidoscope and UCI – Dumfries
- Argyll: Mull Safe and Sound – Mull.
- Highland: HUG – Inverness
- Highland: HUG – Fort William
- Highland: Bipolar Highland – Inverness
- Highland: Rag Tag n Textiles – Portree
- Highland: Rag Tag n Textiles – Broadford

The great majority of groups were of people with experience of mental illness but there was one group of carers and people with dementia and one group of Carers of people with Autism and Learning Disabilities, in some groups there were small numbers of workers present too.

In the Commission we have begun to revisit our guidance on Seclusion. These meetings were an attempt to find out the views of people who might be affected by it or who have experienced it; about it, whether it should exist in the first place and if it has to exist, what might make it less traumatic.

The following pages reflect the views of the people we visited and will be used to help inform our guidance.

There is an appendix which reflects the experience of carers of some people with autism and learning disabilities for whom exclusion can be a common experience.

Should seclusion be an option?

While many people were uneasy about seclusion and many people thought it should happen for the shortest time possible people in most groups (11) saw a need for seclusion on rare occasions or as a last resort.

A choice at best, preferably not used – it can be necessary for very short periods of time.

They felt that it would be particularly needed at times when people are being violent towards other people or to property on the ward.

If the person who is being secluded is a risk to other people then there is a case for isolating the person provided they have the right tools to do so.

Someone was in a room because he was tearing everything apart so it needed to happen.

I would not want to put the person at risk – I have a nasty personality type [of my MPD] that could put someone at risk and would not want this to happen.

It might have to come in at an extreme – then if there was no way of calming them down then maybe then it should happen.

However some people, in nine groups, hoped that, where possible, seclusion could be a choice rather than a matter of force and compulsion.

Seeing it happen is very bad – both could be equally bad. I would prefer to voluntarily go into the room.

If you are agreeing to it, it would be very different.

In four groups some people said that they would prefer seclusion, some in preference to other forms of treatment and some people because they have a strong need to be separate from other people, seemingly feeling that they would like to be isolated voluntarily from other people and sensations. For them seclusion would be a choice and a voluntary action.

It is almost as if you have all your sense overloaded – it is like shelter – respite from the conversations and social interaction that you cannot keep up with.

I struggle with senses – it is the TV and the Xbox and the lights – I can need away from stimulation.

There can be times when I only want to be alone – if I was in hospital there would be times when I would be rather locked up and times I would rather not.

However in six groups, people felt that, by its nature, seclusion could be traumatic and damaging to people's mental health and wellbeing; both the people it is being done to and to people witnessing it. Some people said that it felt like a punishment and should not do.

I experienced assault when a squad of professionals came to me and injected me –it was hugely traumatic.

I got an injection in hospital and remember the last thing I said before they bundled me into this room was 'I don't want to die' – it can be incredibly traumatic.

Seeing it happen is very bad I would prefer to voluntarily go into the room.

In five groups people felt that there may be ways of avoiding seclusion if people were communicated with better. They felt if staff had a good knowledge of the person concerned, there may be ways of de-escalating situations and calming people down that avoid the need for force and there may be safe spaces on the ward that people could go to, to avoid getting wound up and at greater risk of forcibly being put into seclusion.

People also wanted to point out the considerable difference to being put somewhere for a short time to calm down compared to being placed in seclusion for prolonged periods.

In four groups some people said that seclusion should not be used and felt that it could be very damaging.

It sounds too much like punishment.

Being forced to be in a space is not a good idea.

If anyone locked me in I would freak out and would eat the walls I hate being locked in or closed in.

In three groups people were less certain, they felt the need for seclusion depended on the circumstances someone was in and that its justification also depended on how long it was likely to be used for and on the type of space that would be used for seclusion.

In slightly more groups (five) it was suggested that people be asked about seclusion; their views, even if difficult to obtain may help greatly with the decision. Equally when people are well they may have views that they could express to staff or in an advance statement about whether seclusion could be a helpful thing to be done to them.

Maybe ask people when they are well what they would like if seclusion might be a possibility in the future.

*Maybe they should have asked me what would be best for me from my point of view
Could it be an advance statement – I might prefer to be isolated away from everyone not made to socialise.*

In addition people would like to know that it is a possibility and be told of any alternatives to it which they might cope with better.

There was also a question raised about at what point a line is crossed with assessments of peoples capacity which would justify the use of this sort of action.

On a completely different point a few groups felt that seclusion is more likely when there are fewer resources available to support people. Understaffed and over-pressurised wards are more likely to provoke crises in people which can in turn lead to seclusion. Two groups were keen for the Commission to do the research that might indicate whether the greater use of restriction and force is linked to investment in services, austerity and staff shortages.

With staff levels being so low it will increase.

If health care is about human rights it should not be about just having enough staff – and how to approach people. I am thinking of the person that needs help and have it in such a way that is generous and patient with a big safety net – a safe, comfortable, 'heave a sigh', 'I am safe' place.

They also wanted to be sure that there were safeguards in place around seclusion, that there was a common definition of seclusion and that statistics about its use be gathered to indicate how it is being used and if this is changing.

Seclusion as an option instead of compulsory medication

We wondered whether some people would prefer the idea of seclusion to the use of compulsory or forced medication, especially if this included restraint in order to administer medication

In seven groups some people felt that this might be a good option, mainly because they felt that restraint is a deeply unpleasant experience.

Being held down and forced is awful and is horrific – seclusion is better than this.

I would rather flail around on my own than be restrained.

However in two groups people said that they were unsure.

I really don't know - if I was that unwell I would rather someone was able to help I think I would prefer medication.

In two groups some people felt that medication might be a better option, feeling that being locked in a room would be even worse for people than being compulsorily medicated. Some people felt that being left without treatment may be worse than seclusion.

People in four groups preferred to say that if seclusion were to be an option then it should not feel like a punishment and as far as possible should be carried out in a person centred way by well trained and empathetic staff. Ideally it would not come as a shock and surprise to the person it was being carried out on and ideally it would be avoided by using techniques of de-escalation, as well as providing calm quiet spaces. They felt that it should never feel like a punishment.

They should support the person to feel safe and to integrate with other people gradually – there may be times people want to be alone.

It was said that it should be done if it is in the person's best interests and again people said that it can be a bad experience, with one group comparing it to barbaric practices in other countries.

It's just a variant of what happens in other countries, like being tied to a stake.

Again people said that some people would prefer to be alone while others prefer company, for some people being alone is a choice that they would like to make.

And again the Commission was asked to look into whether staff shortages and lack of resources lead to increased use of seclusion.

What is the experience like?

When people talked about experiences of seclusion they tended to say that it was a traumatic and frightening experience:

I did not know why I was in it; I hadn't done anything wrong; they listened to me for ten minutes and sent me to the locked ward and said I would be going into this room – it is hard to suddenly find yourself locked in there – it was quite disturbing – I have a lot of bad memories about it.

It was really hard: they took me into the bedroom on my own and put me on the floor and I saw the needle coming and they took my trousers down and then they just left me - there was a nurse there – they left me on the floor and didn't even pick me up and put me in the bed – they should have put me in a safe place. That's not nice; I am a human being but they just treated me like an animal.

However again some people thought it was sometimes necessary

I have been in the old IPCU [Intensive Psychiatric Care Unit] when every five to ten minutes, someone would kick off and people would converge on them to stop them damaging themselves – it is needed on occasion.

Comments on what a room used for seclusion should be like.

People who had seen or been in seclusion rooms tended to comment that they were unattractive and unpleasant spaces and that they shouldn't be. People did not like the idea of bare rooms with a toilet and a mattress on the floor.

What they wanted was a room that is:

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| Calming | A room with soft colours, soft furnishings, soft subdued lights, maybe with aromatherapy type smells, with cushions and many of the elements of what can be found in sensory rooms. |
| Safe | For some people; a room as above, but with no sharp edges and ample padding would provide safety. Some people think in the extreme the only way of providing safety would be by providing a mattress on the floor. |
| Contact with nature | Some people find access to fresh air and nature very important, maybe via windows or through enclosed fish tanks or by other means. |
| People | While some people wanted to feel totally alone, other people felt that it was important to have staff who monitored them and were able to communicate with them in a reassuring and warm way. |
| Music and sound | For some people music could make a difference or sounds such as the sound of the sea. |
| Food and drink | Being able to have a cup of tea or something to eat could also help. |
| Pictures | Some people would like to see pictures or images on the walls. |
| Homely environment | Some people felt that in some circumstances people would be safe and much more comfortable with a room as close as possible to their home environment. |
| Smoking | Some people wanted to be able to smoke in the room they were in. |
| Cleanliness | Some people were keen to make sure that such a room was kept clean. |
| Activities | Some people would like things to do in the room, especially as they calm down, colouring in things may give some peace. |

Other views about seclusion

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| Rights and recovery | <i>These are people – however they are, they still have rights – it should be all about recovery and should not be seen as a punishment.</i> |
| Outside environment | <i>Being not allowed out – especially if you are an outdoor person – who normally spends a lot of time outside – it can be a shock.</i> |
| Causes of seclusion | <i>We need to work out why seclusion happens to start with – people may be frightened and scared to start with going into hospital.</i> |
| Visitors | <i>Would you be able to see family and visitors when in seclusion.</i> |
| Effect on others | <i>It is a traumatic event on a ward; how do the nurses help other people make sense of it?</i> |
| Trauma | <i>At a time when the NHS is meant to be waking up to trauma informed care – how intrusive is constant obs and the power issues it has and how it re-traumatises people.</i> |
| Dignity | <i>If things are removed like sharp objects and people are not consulted about it: the loss of dignity of having to ask for a razor.</i> |
| Environment | <i>Generally a ward does not feel homely whereas in other hospitals it is a nice friendly environment – why do they not make it more attractive.</i> |

Appendix

Seclusion and units for adults with autism and challenging behaviour

We spoke with 6 carers who were parents of people with autism, learning disabilities and challenging behaviour who were all being treated in a specialised unit.

All of their (adult) children had experienced seclusion and restraint. Their parents felt strongly that the need for seclusion could be reduced and minimised. They worried that the treatment their loved ones received sometimes resulted in higher levels of seclusion and restraint than necessary and had observed it both decrease with different treatment regimes and living conditions and also increase in different environments. Some of them worried that the treatment regime their family member experienced was, itself, a major reason that they reacted the way they did.

We have witnessed someone kicking and shouting –we worry that the reason for challenging behaviour is the unit itself.

If there were more staff he could be taken out. There are generally only a few staff.

If they looked after him in a friendly caring way there would be no need for seclusion.

It is possible to have non- restrictive environments in the right circumstance.

With the right people and the right care he was fine but he didn't get that in between time – but once the atmosphere changed he changed.

The environment in that building is not conducive.

As soon as the melt down is finished everything is ok – that's it gone.

For them seclusion was very much a rights issue and the experience of seclusion and restraint a traumatic and unpleasant experience.

The worst environment is sitting alone in his room. A few months ago he was in the room alone for 30 hours a week; that is a major issue.

But here we saw him on the floor with all the staff on top of him and drugs.

He is still being left alone in his room quite often. They will only go in in twos which may be because he may attack them; or in case we accuse them of attacking him. It is attitude : he could be thinking they are intruding on his space.

Restraint can be needed but it and seclusion or being locked in can be minimised.

We take food in, they unlock the door and take it in and lock it in there.

I am told I cannot be there at meal times.

Seclusion: It's a breach of human rights and is a restriction of freedom.

They strongly felt that the opinions of family can be key in working out how to treat their adult children. They felt that they knew them better than anyone else and often had a much better understanding of what their relatives needed. But while some of them were now happy with their involvement in their relatives care and the way they were being treated; Most of them had, at times, felt that the health service had actively sought to exclude them from contact with their family member and from taking part in informing the treatment of them.

I know what he needs; they know what he needs but do not provide it.

They were dismissing what we knew helped; we knew the solution: if they had just listened to me. They say I am bullying, intimidating and rude to the staff and that I am stressful to him but X just grabs my hand and says 'Sit here, sit here.'

He was kicking and calling for me (for five weeks) That was wicked; they should not punish me and him in this way. I suspect they do not have enough staff; the room is completely empty I do not know any of the names of the other people who are there. I have not been allowed to see any other patient due to confidentiality.

I was fighting them after 18 months about the treatment order. She said 'I am on the other side' She said 'Just be aware it is my job.' We realised we had no allies; so when we tried to go for guardianship they said we were not suitable

We found somewhere in Scotland where he could go but they said 'We don't have the money.' They said "If the placement fails he will go to X hospital". But they put up the meds to the higher level. It drove him mad again and he ended up in the X centre. We said "He is not psychotic, he is behaving normally like an Autistic person." but they would not accept this. Because we complained they stopped us seeing him.

The best training staff could have got would be by listening to the parents; they are the experts by experience: they understand their children. We are the only ones who know them fully but it was always: leave it to the professionals

If staff know the person and understand him then they can treat him as an individual and if they can't speak for themselves then their carers or representatives should be able to speak for themselves and for him.

A few weeks later the psychiatrist asked for the presentation and I gave it to her and she has provided much of what I said.

To hear a professional say they would never do a diagnosis without a relative/carer was very refreshing, having that perspective is vital

We asked for a review of XXX when they were renovating the accommodation. The second report on the regime that was there was scathing. We got both reports saying it was good accommodation and that the regime is pants. They took it on board and we talked about what people with autism with complex needs require...

They had observed shifts in the quality of life of their adult children with different treatment and living environments; some people having good experiences in the same unit that other people had had poor experiences in.

He is happy there, he is locked in – because he is a pain in the neck when he is out: it is a safety thing: there is always someone the other side of the door. They seem to understand him and are very good with him. He goes out and about and if he doesn't want to go out he doesn't.

Monday he goes swimming, bicycling, trampolining – swimming at XXX and going to it on the bus which has been a great treat for him as he has never been on one before. Apart from that, they take him shopping and help cook his meals. Yesterday we sat down and had a meal with him in his room (we are not allowed in the kitchen.) Their attitude has changed; one person plays guitar and music.... it is like chalk and cheese

One day they said I couldn't come in because he was not well and I said "Then I must see him." and I said "I will stand there as he needs to see me." Eventually they let me in and he said 'hello mummy' and gave me a big kiss.



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