mental welfare
commission for scotland

How much we want to keep our autonomy when being cared for

Service users and carers information

July 2019

The views of people with lived experience on how much we want to keep our autonomy when being cared for

Mental Welfare Commission for Scotland

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The following paper reflects the voice, experience and opinions that people with lived experience and carers, as individuals and as groups, provided on the subject of autonomy and personal responsibility. 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.

Service user and carer groups, or groups for people with mental ill health and groups for families and friends, 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 of the 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.

Contents

Summary

What were we trying to find out?

We were trying to find out to what extent people wanted to remain in control and be responsible for their lives when being treated for a mental illness, and to what extent they wanted to relinquish responsibility and decision making and be looked after.

Who did we ask?

We asked 165 people in 12 focus groups across Scotland, mainly consisting of people with lived experience of mental illness but also friends and relatives and a very small number of workers.

What did we find out?

We found out that the desire to have autonomy compared with wanting to give away some responsibility varied and that sometimes people wanted a combination of the two. This depended on a number of things, such as how ill a person was (the more ill they were, the more people tended to want to be free from exercising a lot of responsibility), what their past experiences were, what stage of life they were at and who they were as people. Some people very much wanted looked after while others desperately wanted to remain independent at all times and found any form of coercion or control offensive.

We also found out that people's desire for autonomy varied considerably with the treatment and conduct of the people looking after them. If people were rude and dismissive or patronising, people not only found it hard to trust them and accept care they also found it hard to participate and co-operate.

We also found out that some people could not participate in care or seek help and that this could be because of attitudes, stigma and illness.

We found out that some people very much wanted help and support and a chance to be looked after but some services were such that they would not willingly approach them. Some of the services that they wanted were not available to them, or did not exist, and therefore the question of whether they wanted to have autonomy or give away responsibility was irrelevant.

We also found out that many people rely on their families for support and that sometimes families are not able to provide this or do not have enough information and help themselves to help.

Introduction

In late 2017 and early 2018 the Commission's engagement and participation officer (lived experience) held meetings in focus groups across Scotland to look at the balance between having control and autonomy and being supported and giving away responsibility when undergoing treatment for mental ill health.

He met 165 people in 12 groups.

The reason for this was that in much of the debate about supported decision making and substitute decision making, and in much of the policy landscape to do with mental health, there seems to be an assumption that people should want to participate as much as possible in their treatment, that they want to be considered as equal and valued partners in their care, and that efforts to preserve autonomy and control of the decisions taken about them should be uppermost in people's minds.

Anecdotally he had met many people who very much wanted as much of a say as possible in what happens to them when being treated for mental illness but he had met maybe as many people who talked of the need to sometimes give away responsibility, not make decisions and be looked after when struggling with their health.

He wanted to test out what people thought of this and so consulted in advocacy and support groups across the country.

He met people in:

- Strathclyde – Glasgow – Bridgeton – Restart
- Strathclyde – Glasgow Maryhill – Restart
- Strathclyde – Glasgow Centre – Glasgow Bipolar group
- Lothian – Edinburgh – Bipolar Edinburgh
- Dumfries and Galloway – Dumfries – Support in Mind and UCI
- Forth Valley – Alloa – Klaksun
- Tayside – Perth – Plus Perth
- Tayside – Dundee – Dundee Bipolar group
- Tayside – Dundee – Dundee SUN
- Highland – Lochaber – HUG
- Highland – Inverness – HUG
- Highland – Wick – Caithness Mental Health Support Group
- Highland – Thurso – Caithness Mental Health Support Group

What we found out

The following was mentioned frequently (in 10 to six groups):

- Different situations can cause people to want more, or less, autonomy and responsibility.
- Staff attitudes can influence what people want.
- People sometimes need to be able to give up responsibility.
- Lack of services.
- People should retain their autonomy.

Different situations can cause people to want more or less autonomy and responsibility

The need for a balance was mentioned the most times in these meetings. The degree of support a person needs and the degree of responsibility they might relinquish varies and can change over time for many reasons.

Often the balance needed between relinquishing responsibility and keeping autonomy depends on how ill a person is. If they are very ill then they may need and wish to be looked after and want not to take many decisions for themselves, but at different points people may wish for and need more control and autonomy, especially as they begin to recover.

- *"Depends on how ill you are; if I am really ill then please look after me but if I am not really very ill then I can just cope and don't need controlled."*
- *"At your worst you may want looked after but when you are more well you could, and should be, doing more for yourself."*

However this balance can vary from person to person, the need to be in control may be very strongly felt with some people and be less so with other people and this may need to be reflected in how treatment is provided.

- *"It's hard to say other than it depends. It can depend on your personality and how you have been brought up."*
- *"It depends on the person and their state of mind. When he is manic he wants to be in control of everyone and when depressed, he would let people do anything and wants them to."*

The need a person may have to hand over control, compared to autonomy, is also likely to change over time as people's lives change and they become more accustomed to their condition and ways of dealing with it. It is likely that it will also vary with their own self-belief and confidence.

- *"I recognise a swing to and fro; month to month; year to year, between how much I want to sit back and relax and have peace and have people take things over. The problem is trusting people to do this and also when I start to feel better; feeling able to take control again. There are people who want to look after you*

and do not want to let go that role. I then act against it and feel insulted and angry but this is not really easy as I have said I do want to be looked after."
- *"As I have got older and learnt what bits of me are behaving this way through illness, I have learnt what I can abdicate from me and also what I could be taking on and what I shouldn't sink into."*

In addition there are emotional consequences to asking for help or giving control away. It can be very hard for some people to accept that they need looked after and equally it can be very hard when people have little choice in this.

- *"I am someone who always strived to do stuff on my own, it never occurred to me that I could ask for help. It can be hard to admit that I, like, with my permission, let them take over some things for the first time in my life."*

Sometimes people may feel conflicted by the need that they have to be looked after and, despite wanting to retain control, may need convinced to give up some of their autonomy. If that happens, people still need to have a range of choices open to them and constant review of how much control is taken away from them.

- *"Protecting people is needed. Your brain needs a rest from you. So if you back off it, and other people would ideally take over but the problem is when a person resists that, which I hate the thought of; but if it is. There is what you know and what you believe and they are partners; but in this state it is broken. You need someone to support the knowing part of you to do the knowing."*

Equally the needs of friends and family can need to be acknowledged; the pressure on family may be such that they need some distance from their loved one and equally the degree of emotion may mean that a person wants to be away from their friends and family so that they do not witness some of the more distressing aspects of their illness.

- *"I think it's a bit like I can do so much and yet there are times when I cannot care for him at home and then, I am not a doctor: there can be times when you need someone with medical skills."*
- *"Some people would like privacy and help. It can be difficult when you do not have distance from your loved one."*

A lot also depends on who a person is asking to provide support: to be vulnerable enough and confident enough to pass over a degree of responsibility to another person needs an appropriate response from the people and services that are asked to help.

- *"It fluctuates and is on a continuum and depends on how much responsibility we can take. If we are lucky enough though to have someone trustworthy; we hand over responsibility."*
- *"We do not choose to be ill and do not choose not to manage. We need support and maintenance and self-management and self-responsibility."*

How attitudes can influence the degree of support we want

The experience some people have in hospital can make them resent any attempt to take some autonomy away from them and can also prevent them from accepting or wanting help. In order to want to feel cared for and supported and to be able to work with helpers, people need to feel that they are respected and that, where they can, they will have as much say and equality as they wish. They need to feel that they have rights and, as far as possible, choices.

- *“Show real empathy; don’t make it sound like an order.”*
- *“I had not understood just how intrusive and overbearing people can be in hospital. If someone has a mental illness, the assumption can be that you are capable of nothing.”*
- *“Someone close to me went to get a pass that day. It is not a welcoming ward. As we were getting ready to leave, this nurse tries to give me his money and medication and I said ‘What you doing? This is not mine!’ For someone with little autonomy; you are taking away the one bit of responsibility he had for himself. I made my dissatisfaction clear and said he has to be responsible for his own medication and money. You need to be careful but it is his. That was a balance of independence and being looked after.”*

If people are not given information or explanation, and if they feel dismissed and patronised or ignored, then they are not likely to respond positively to the people charged with their care.

- *“I wonder if part of it. Pride often comes in; it depends on how the help is offered. If it is offered or imposed in an authoritarian or patronising way, where they imply they know best, I quite honestly, resent it. Even if I know what they are saying is right I resent it. If they let you know they have been there too and have empathy, it makes it easier to admit to yourself that they may be right. You need a relationship that is as equal as possible: where different points of view are listened to. If I hear it in the right way I can take it. But if it is cold I could ignore it.”*
- *“They take your independence away; if you tell them your problem or you have a fear; it is not sit down for a half hour for a chat instead it is ‘what about PRN’* [pro re nata; medicine prescribed as needed]*?”*
- *“It is like being primary children where you are told what to do or in hospital where you are not allowed to touch each other.”*
- *“I have bad memory and concentration. They say ‘Don’t bother talking to her, she does not know what she is saying’. I need a chance to get control of my life again but they say ‘It will be months before you are ready to do that.”*

A key element in this, both in and out of hospital, rests in being able to trust the people who are providing support and care

- *“I would rather be by myself when I am not well. Unless you are with people that you can absolutely trust then you are better off with yourself.”*

Some people find it hard to believe that this can exist in the NHS and some people believe that the training medical professionals get, acts against the very qualities that they want from their helpers.

- *"The thing is that they are trained medically and so empathy and sensitivity does not exist. How is it possible to have much trust in them? I have never come across a doctor who I could trust."*

Where people do find people that they can and do trust in the NHS, this can make a considerable difference.

- *"I have two nurses who are fantastic, who I trust. These two are something else; they help me to go out; they don't just push me out, they take me out."*
- *"I trust them enough to let them laugh at what I am saying rather than say 'What the heck are you saying?'"*

Equally, the life experiences that people have may mean that they are very wary of other people, especially professionals. The act of trusting someone and allowing themselves to be vulnerable and looked after can feel very threatening.

- *"If you could trust people: you need to regain the trust. You want to regain the trust, you need to be able to do this but it can be difficult when you have had bad experiences. You need someone alongside you who can recognise that it is not necessarily the situation you are in but triggers from the past that cause you to react the way you do."*

People sometimes need to be able to give up responsibility

Many people said that there were times when they need supported and when they can welcome being looked after. That sometimes they need to give away some of the control and responsibility they carry in their lives.

- *"The poor brain needs a blooming rest."*
- *"The value of the Community Mental Health Teams; they're the first line that says I am vulnerable; that says I need to be in a safe and secure environment. This is reassuring: I can go there and not have to hide my condition. I worry in the community how much people know how I am."*
- *"If I am in hospital I like them doing their job and doing things for me. It is a relief. It can be a nice thing that people care."*
- *"Of course you do. You need to give away responsibility when you are ill."*

However the ability to ask for support and to know that people will be looked after and cared for does not reflect the reality of some people's lives. They may ask for help and want to be cared for and yet, having asked for that help, find that it is denied them.

- *"When I am really depressed I would rather let them take care of me. But then they admit me and put me home the next day. You get in there and the next morning there are a few people sitting around asking questions and they say 'You* *can go home.' and yet you need the help. It is hard to get in the place when you need it. It is easy when you don't want it."*

Some people may lose much of their ability to cope and live independently and at such times may need to relinquish responsibility. However this is not necessarily a relief to people; it can be frightening and worrying for them and may mean that they feel their views are not respected as much as they should be.

- *"When you are psychotic you don't know what is going on and just want out and are scared to look at the window or the door. In this state when the voices are too much and you are desperate and are scared to go to the toilet or sit in the canteen you need looked after but at the same time when they are monitoring you and medicating, you want left alone, they are pushing you and pushing you. You can be petrified."*

For some people, their ability to cope and manage safely becomes so impaired that they may not only have to get support and relinquish responsibility but they may on occasion need this to be done against their will. Despite this they need people to acknowledge the distress this may cause and also need to continue to have their opinions and knowledge respected.

- *"You need detained and sectioned at times when you are not well."*
- *"People can be walking about the streets and bashing bottles and need people to help."*
- *"That is when you should be receiving treatment compulsorily; people need to pick it up. A couple of years back, I had a broken toe and became very violent. It left me unwell for a year. If they had picked up on it earlier. I had to get a lawyer to get an 'X Ray' to prove my toe was broken. Medication didn't mix and was bad for my health."*
- *"A lot of the time if I hadn't been taken, I wouldn't be here today. It kept me alive. My partner told them that she couldn't keep me safe. When I got better I realised I needed help. Sometimes I don't realise."*

It is not always services and professionals who people ask for support and who they want to look after them, it may be family.

- *"People had to take control because I couldn't eat. In order to survive; someone needed to take control of my life and help me. I still have troubles with the thoughts. My daughter took control; I didn't know what was wrong. I had all the treatment so mentally I am now stronger. I used to call the eating disorder 'the minx' so we could beat it. I got all the treatment I needed. I still get all the thoughts but now I am much stronger and in control and my family can see if I am going downhill and help if I need it."*

Lack of services

A painful reminder of some of the issues behind the discussion about how much support autonomy and responsibility people want to have over their treatment was the fact that many people felt that they couldn’t get services in the first place, had services that were so poor that they did not want to use them, or wanted services that do not currently exist, therefore making some of the conversations quite irrelevant.

Some people had particularly negative views about some hospital services and would not willingly use some of them:

- *“The reason I sought early intervention is because I knew I would go to [hospital]; if it were [hospital] I wouldn’t have gone.”*
- *“Hospital makes you worse rather than better. I would rather the community. I was only detained for a couple of months in the community; I had to attend appointments. I don’t like hospitals, they make me worse.”*
- *“I was frightened to go in the hospital because of my fear of other patients, I knew [hospital] years ago as my mother-in-law spent years there and was terrified of going into hospital because of this.”*
- *“We had a couple of ex-prisoners who said prison was more comfortable with better facilities and food than hospital.”*

Quite apart from not wanting to use certain services, some people also talked about how there was a lack of any service for them to use:

- *“In the past when we were phoning up saying we were concerned about people they were saying there was nothing they could do: they should just crash and burn until people had to intervene – there should be something in between.”*
- *“There are not enough beds.”*
- *“It can be impossible to get help or into hospital. They say ‘No you are fine; go home.’ and then they say ‘You are kind of pushing us to send you down there’. It gets you down.”*
- *“If you make a lot of wrong decisions and do things that hurt other people; that needs recognised and supported. People are just left by themselves. I feel there was no one to speak to or see and felt so alone which made me feel worse. If I had had someone I might not have done this or if I had somewhere to get away for a day or two.”*

Some people also sometimes felt that they needed other services that do not exist or are few and far between.

- *“I would prefer a safe house or a half-way house. I can need to get out of my environment and I wouldn’t want someone in my house: I would be really embarrassed. I do not want a permanent escape but somewhere to go to when I need to.”*

People should retain their autonomy and responsibility

Many people had concerns about losing their autonomy, both when it was taken from them against their will and also because they felt they needed to remain responsible for their own lives. Sometimes this was because that is how they approach life and sometimes because there is no one they would want to rely on or because they worry that by losing faith in their own abilities they will lose more autonomy than they wish.

- *"You sometimes need to push yourself to do things; sometimes you need to shove and shove at yourself to get up."*
- *"Realistically you just need to trust your own instincts."*
- *"But you can stop trusting yourself and how to live and end up losing independence."*
- *"Sometimes you just need to do things on your own but not with the staff."*

Some people resent the fact that people can assume that they are less capable than they feel they are and wish that their ability to live their lives and make their own decisions was better respected. They feel that, after times of being less independent, they need to be given back the ability to take decisions and live their lives, more quickly.

- *"In the past once you have been given a label or diagnosis that's it. The control should go straight back to the patients. It can be very difficult to wrest control back or get discharged."*
- *"They say you can't make your own decisions but I think you can."*
- *"I was ill for a few weeks but they kept me in for months."*
- *"You know what your body and mind needs."*

Some people feel that the way they experience ill health will influence the degree of autonomy they want to have in their lives, and also that taking away the control that they have would not have been beneficial because of what they were going through at the time with their condition.

- *"I am quite psychotic so I don't want much control. When I was younger I would be flying off in fantasies and then no control would have helped."*

Some people experienced loss of autonomy and control because they were detained under the Mental Health Act, some of them felt that this was wrong and should not happen.

- *"I always get detained. I think you shouldn't get detained."*
- *"I was detained in the community for two years. I didn't like it you, couldn't go anywhere."*
- *"It is worse when you have responsibility taken away from you without your consent and when you do not feel it is necessary."*

Mentioned less frequently

Mentioned less frequently in five groups or less were the following factors that might have a bearing on the degree of autonomy and responsibility a person wants to or can have:

- People don't seek help.
- Advance statements and care planning.
- Knowing the person.
- Family.
- Early intervention.

People don't seek help

There are many reasons that people will not engage with services or seek help and therefore the degree of autonomy and responsibility they seek, or have, may be seen in a different light.

- *"A lot of people with mental illness don't seek help at all – they may lose their job or not get benefits."*

Sometimes people cannot seek help because of the illness they have in the first place. It may cause them to avoid services, or it may mean that they are not aware that they might need help and are therefore not given any support or help.

- *"You can get to the stage where you do not know you need help."*
- *"You don't feel like reaching out so you get left alone to yourself."*
- *"Sometimes you do not know that you are that way, you need other people to look out for you."*

They may have had bad experiences with services and therefore avoid them or they may be suspicious of services, which may also be bound up with the stigma around mental illness and mental health services.

- *"You can feel paranoid when you go to your doctor."*
- *"It is bound up with stigma."*
- *"When you are unwell you push everyone away because no one listens to you."*

Advance statements and care planning

Some people mentioned both care planning and advance statements as ways of ensuring that they exercise some control and a say in their treatment. They can both be ways of influencing future treatment and participating in, and being informed about, care and treatment. However they do not always deliver the results that people seek:

- *"I did an advanced statement; the first two things they offered me were the two things I said I didn't want in my advance statement."*
- *"In a hospital setting a lot comes down to care planning and our input. You may have a care plan but most patients don't know what it is; they will look at you*

blankly. They sometimes make no effort and have standardised care plans. It should be constantly reviewed."

- *"He had it for 40 years. He was that frustrated; they just did not listen to him. He then took his frustration out on them. He would get that worked up and would rant and shout and bawl. He would say 'If they knew what was going on with me, if they just listened to me, if they knew my thoughts on medication.' They worked out their own plans. They should listen to what works for us; like our dose of medication or the time we take it."*

Care planning and being involved in care planning can help both with future and current care, and help people come to decisions or agree or not with treatment. And help with that degree of autonomy and control that people seek.

- *"When you get care plans, you can't think of these when in crisis; maybe we could have a copy at home of what we have agreed to."*
- *"When you are well you can do a care plan and this leads to the right decisions. And family and friends realise you are in trouble and I will argue with them and they will say 'You wrote that down.'"*

Knowing the person

If staff know a person well, then they are much more likely to be aware of what a person may want and what does and doesn't work with them. It is much more likely that human connection will promote participation and partnership and an indication of how much autonomy a person wants and should have, than when relative strangers are meeting.

- *"You need people who know you and are aware of you and know when you are on a downer. Whilst I see a new person; if I ask for lorazepam they will say try distraction techniques but if someone already knows me they will know I mean it and need it."*
- *"Know the person, recognise the signs."*
- *"You go in to a see a psychiatrist once every six months; you cancel; you see a locum and do not know him. He asks how you are and what you want. Where do you go? You do not even know that person! What do you do? It doesn't fill you with confidence. What if the doctor is making you paranoid because you don't know them and they don't know you?"*

Family

Some people were keen to talk of the importance of friends and family when discussing how much autonomy they should have and how much they might want to be looked after. They talked about how friends and family provide support and care and have a great need to give the information they have about their close one's needs and wishes and in turn be informed about their close one's care. They also said that often it is family that provides the support that is needed until they are no longer able to cope.

Early intervention

Some people said that the earlier people got treatment the more likely they would be to retain autonomy and the less they would need supported.

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