

CAPS Independent Advocacy

The comments below represent responses, gathered from CAPS collective advocacy groups, from people who identify as having lived experience of mental health issues. The group chose to answer the questions from the examples given in the documentation on the Independent Review of Mental Health Law website.

1. Who or what brought you into contact with mental health services? For example social work, police, GP or someone/something else?

“My GP, who was refusing to give me a letter for the DWP.”

Attending the GP surgery for insomnia and the police were called and I was arrested, before being taken to the Royal Edinburgh Hospital under short term detention order.”

“Educational psychology”

“I have come into contact with different services at different times through my GP, crisis centre, checking on google etc.”

The GP seems to be the gate keeper and this means you are relying on the GP’s view of mental health positive/negative – do they know what’s out there, can they signpost well?”

2. Do you know what law, if any, was applied to you?

“NO”

“No – but when I requested my notes I was told they may have been lost! They were unable to tell me the policy on retention of medical records and my GP had not received a copy of these so I was unable to see them.”

I did read my notes a few years ago but when I asked for them again they have disappeared!”

“I was placed on a short term detention order – but what I needed was a place of safety and to see a doctor. Instead of that I got a short term detention order”. I found out about this once I was in hospital. I felt like I was being punished for not complying with police.”

“I feel like you are often being lied to and not being communicated with”

3. Did you get the help and care you needed, and did you get it at the right time?

“NO”

4. Did you feel your rights and wishes were respected?

“NO”

“I have had things that I have asked for but always seems to be huge hassle and it often feels like they are trying to dissuade you if they don't agree.”

I tried to get advocacy but it never appeared and I had to get my lawyer”

It was a huge hassle to try and organise tribunal when in hospital I didn't receive any support.”

I Felt like I was being passed from pillar to post and they were not communicating with me.”

5. How did you make your rights and wishes known?

“I wrote an advanced statement with the help of an advocacy organisation; my GP refused to sign it”.

“My psychiatrist told me I didn't need an advanced statement!”

“I am finding it hard to keep my wishes up to date because of current crisis. It is difficult as one medication I prefer is no longer available and I have not been able to discuss this with my psychiatrist.”

6. Did you feel what was happening to you was properly explained?

“NO, I felt very much coerced by my GP and the CMHT”

“It's hard to say as I was suffering from mania and found it hard to sleep, don't remember a lot of time being spent trying to explain anything to me”.

“They tried to explain but I was having none of it. I did eventually hear about advocacy and having a named person. I got in contact with my lawyer but not advocacy service”

“No one tells you what is going to happen and what your rights are. I asked if I could have a man or a woman, but I was told we always work in pairs. Also, when I did see someone it was a man and you go into a room like a police station”

“I have difficulty seeing my psychiatrist, they refused to see me when I wanted information which meant I had no way to get it.”

"I was kept waiting for so long when I was sent to the out of hours at the Royal Edinburgh Hospital, which did not help to decrease my anxiety. My basic needs were ignored (not asked if I would like a drink of water even) on top of which my own safety was ignored, nobody checked on me, and I could have harmed myself."

"No one spoke to me about what was wrong! Lots of conversation between them but none with me."

"Waiting at hospital there seemed to be no proper procedure. There was no equality of treatment. When I was first admitted I was given bunch of tablets - not told what they were, what would happen when I took them. I did ask what the side effects would be and they did give me book describing the meds, and although they asked me not to share this with other people there it definitely helped me to agree to take the medication once I had the information."

"I did get information about medications after I asked but I was concerned with some of the side effect like 'sudden unexplained death'! Nobody had a conversation with me about them it was just a leaflet."

"All nurses were in one room like they were trying to avoid spending any time with the people on the ward, like – cat and mouse, mouse and elephant, elephant in the room, showdown time!"

"At one point a registrar who had promised to come and see me to have a conversation about my concerns, when I was walking in the corridor and saw he was ahead of me then proceeded to hide on the stairs to avoid me when he saw me!!!"

7. Were you given options for treatment or support?

"No, they coerced me."

"I was not given options over treatment; it would have been nice to be trusted and not treated like a criminal"

"Punishment medication- I felt like the medication was being used to control and punish me, this left me feeling suicidal".

"No – 4 nurses grabbed me, pinned me to the floor and forced an injection on me, his was an awful experience."

"No it felt like a concentration camp"

"I was given options, but it was through a lens of their preferred option and if I chose differently they implied that I was not being co-operative or being uncompliant."

8. Did you get the opportunity to discuss any previous plans or wishes you may have?

“NO”

9. Did you feel safe at all times?

“NO, I felt profoundly unsafe.”

“I didn't feel safe as one person threatened to cut my head off another said he would find and kill me”

“I had a similar experience, a place of safety is quite ironic -it's still a sensitive subject for me. You have your liberty taken from you -it's not compatible with human rights. I was also threatened with death when I was detained”.

“I have been taken into hospital to keep me safe but not sectioned. I had things stolen from me and also felt unsafe – it was unhelpful. I was told this was not a good environment for me but not given any other options”

“I saw lots of people being dragged about when I was in a waiting room, not only not safe from others, as nobody checked on me I didn't feel I was safe from myself at the time felt like I was on display to people passing by it was really distressing.”

“There was no privacy”

“I was bullied on the ward, 2 people were picking on me and being physically violent, my advocate suggested that I was moved to another ward which I did.”

“In a young persons' unit and I was attacked by another resident, when I told staff they suggested she was just trying to get to know me and that she was adjusting. She attacked someone else and later found out she had a history and was supposed to be accompanied by staff at all times. This made me feel very unsafe.”

10. How did your experience make you feel?

“Terrified, with a total loss of trust in GP and NHS”.

11. Did you feel you were treated with dignity and respect and that your voice was heard?

“NO”

“Absolutely not!”

“My voice was only heard when I threatened to kill myself, and that they should record that!”

“I would go for days without seeing my medical staff.”

“Staff vary seemed like they spent more time doing paperwork, not much time to spend with people on the ward”

“Could be weeks before saw anyone – did not feel respected or listened to at all.”

12. Did you feel there was something about you which meant you were treated differently? For example, gender, age, race, religion.

“YES, I reported discrimination and health abuse - organisations not using the Equalities Act for my physical diagnosis of chronic pain. They (and the NHS) tried to coerce me to talk about psychological issues instead. The NHS/GP carried out no physical assessment whatsoever. I have now discovered some of the symptoms I was reporting are part of a serious physical condition, now requiring surgery. Had I been correctly diagnosed at the time, I could have avoided surgery. This has ruined my life.”

*“I was in an inpatient unit voluntarily but couldn't get access to social work etc. I was also **told** I was being taken in it was not discussed, and I was not really consulted about this. I was a young person at the time -it's hard to say whether I was treated differently because of my age”*

“I think my gender was an issue I can come across as aggressive when I am unwell and I think this is why I was detained, and also that I see police as a threat.”

“For me it might have been a gender issue but also people couldn't understand why I wasn't with anyone if I am unwell. It wasn't until I threatened to kill myself told them it would be their fault that someone came to help. It wasn't good to have to be in this state before I got help”

“I felt that I wasn't treated seriously with my own definitions of struggling with food issues and they were very dismissive! I Didn't fit into their box of what eating disorder meant!”

13. Are there ways in which you think your experience could have been improved? For example, you might think that more needs to be done to support people to make decisions and have their wishes respected when they are very ill. Or you might think that we need to do more to avoid people being subject to compulsory treatment.

“There needs to be full accountability in place. I was powerless with regard to their coercion. No-one would listen to ME. Coercion is violence. I felt terrified. The CMHT suggested my reaction (of profound fear) was a sign of mental illness. They had no concept of the fact their behaviour was traumatising me.”

“For me it would be to not be there in the mayhem”

“It's often the little things, often the GP doesn't know where they can signpost you to. Also, how services respond to people – being stuck in a room for hours by myself waiting for treatment because no one checked on me. If there was a volunteer or

peer worker to check on people and make sure they have food, water or an idea of how long I would have to wait this would have helped so much”

“Having one continuous person was helpful for me but then my social worker retired and that was the end of that. She told me how things were and what to expect”

“For things to improve at a faster pace, not just sticking to the status quo being quicker to respond to change.”

“Less hierarchical structures.”

“More concentration on de-escalation methods, having more options for non-hospital treatment at an earlier stage.”

“Notes being shared with people without having to ask for them. Having your hospital record being sent out to you so that you have a record of your stay. A lot of times people do not remember everything that happened whilst they were in hospital and it could be a positive thing to reflect afterwards with accurate information – but regardless would be good to have the choice.”

“Procedures at MHAS and in wards on display for people to be able to see what they can expect while they are waiting or while they are in hospital – positive for transparency.”

“Ensuring that at the heart of everything is AS MUCH personal choice as is possible and being able to show people at all points that this is case.”

For mental health professionals to validate people... to always have respectful interactions.”

14. Did you receive any support to help you adjust to your life after having treatment? For example did anyone speak to you about housing, money, education or employment, and how support with those sort of things might help you?

“NO, I had a mental breakdown, lost my home and moved into a homeless unit. I then felt blocked as I tried to raise a complaint. I got no healthcare and, as yet, no justice”.

“The social worker was very helpful with sorting out housing and helped me to find the place I am in now and it has been a huge success”

“My lawyers were very helpful always willing to speak and help when needed”

The local council and housing association in my emergency housing were very good when I came back from hospital. IHTT were also very good.”

“The job centre helped me to go on a scheme where I could work for a year and receive benefits (not be signed off). This helped me to be in my current job and allowed me to have the confidence to stay (Jobcentre disability advisor).”

“When I was first in hospital I was in college and other people on the ward were really helpful with what benefits to claim. I later found out that if I had stayed in hospital I would have received support to get housing but I was not informed by any staff in the hospital that this was the case and so I was homeless for 2 years.”

“I felt like I was left on my own when I was discharged, I no info and had to figure it out on my own.”

15. Do you think the law could do more to help people with other issues that might affect their mental health, like housing, money, education and employment?

“People have to understand that social issues cause mental distress, and not engage in a medical model labelling (stigma) of the person as having some kind of inherent psychological problem. Human rights, including legal redress, have to be proactively applied in all cases”.

“There needs to somebody to be there for the whole system so that people are not left in holding patterns.”

“Increased parity with access to benefits for Mental Health and Physical Health.”

“Diagnostic overshadowing - people with Mental Health should have the right to demand that physical issues are dealt with independent of any mental health issues that are known to medical staff. It is often the case that when you go to a GP with something physical but have mental health issues that you are not taken seriously.”

“Mandatory training for GP’s in Mental Health”

“Mandatory training for Police officer in Mental Health”

16. Do you think the law could do more to raise awareness of, and encourage respect for, the rights and dignity of people with mental health needs?

“YES, there needs to be a clear statement from the NHS and GPs that the so-called 'mental illnesses' are NOT medical science, but subjective labels. People should not be forced to accept the medical model (pseudo-diagnoses + medication) or psychological/analytical, or behavioural, approaches as the authority on their distress. If you have the full facts and believe in it, then you can choose to use it. However, the medical model must only be one choice of many, i.e. include holistic psychotherapies, complementary medicines, social approaches and recognition of spiritual experiences. GPs should not be the gatekeepers. Choices should be accessed via neutral (non-medical) peer support services.”

“I didn’t know anything about this act until I was sectioned – education and awareness raising is crucial and sorely lacking”

“I have always had the experience of not being treated at the Royal Ed and have had to get up and leave. Staff don’t seem to know about the MH act.”

“We seem to be holding more people against their will than in other countries”

“I was held in hospital for too long -it was unnecessary”

“Easy read versions of the act, and displayed in more places, like GP’s in-patient units, CMHT waiting rooms etc”

“Better, easier ways to access recourse – complaints against services, this takes too long and is a difficult processes. The system seems nepotistic, it feels like there is a lack of independence and a tendency to close ranks.”