HOUSES OF PARLIAMENT

Joint Committee on Human Rights

Oral evidence: Conditions in learning disability inpatient units, HC 1811

Wednesday 12 December 2018

Watch the meeting

Members present: Members present: Ms Harriet Harman (Chair); Fiona Bruce; Karen Buck; Jeremy Lefroy; Baroness Hamwee; Baroness Lawrence; Baroness Prosser; Lord Trimble; Lord Woolf.

Questions 1–19

Examination of Witness

Witness A, individual with learning disabilities;
Witness B, individual with learning disabilities.

Q1 **Chair:** Thank you very much, […] for coming along and talking to us this afternoon. As I explained to you earlier, I chair this Committee, which is called the Joint Committee on Human Rights. We are half Members of the House of Lords and half Members of the House of Commons—MPs. We are concerned about human rights and the human rights of everybody. We are really grateful to you for coming along and talking about your experience, what you make of it and what you would want us to know about.

Of course, you have [name of individual] with you, who is here to help and support you. As I said to you earlier, there are no right or wrong answers. This is definitely not a test or an exam. We are just very grateful that you have come along to talk to us, because at the end of this we are going to write a report with recommendations to Government and to all sorts of other people, and it is important for us to hear from you before we write that report.

Perhaps I can start by asking you to say a tiny bit about yourselves, whether you knew why you were detained and whether you thought it was right.

Witness B: I am 49 years old and I have a learning disability. I work at [name of institution] as a consultant and have been in the role for just

over a year. [The organisation] is a self-advocacy organisation for people with learning disabilities, run by people with learning disabilities. I am an expert by experience. I was in secure hospitals for three years when I was around 19. My experiences there were not good at all.

When I was 19, I got into trouble with the police. I did arson when I was younger. I lost my brother when he was 16. I was in a bad place at the time. I ended up going to court. I broke my bail twice. I ended up going back to court and going to [name of prison] for six weeks, which I did not like. I hated the prison and its long wards.

Then I ended up going to [name of institution]. I also did not like it because it was a secure unit, but there I had the help and support that I needed to get back with my family, because my family disowned me when I went to prison. [Name of institution] closed and I had to be moved again. I was told I would be put on the open ward and would have all the support I needed when I moved. I ended up back on the secure ward, so I was not happy.

Eventually, I built up the confidence to move out of [name of institution] and got my own place, and since then I have been happy. I did not like it before. I came out covered in bruises. I was not happy that I was put in prison in the first place. I should have been in an open ward with support. I came out with all the support I needed. Eventually I got married and now I have been married 20 years. I also have four stepchildren I have brought up, so I am much happier now than I was back then.

Witness A I am 31. I now live in supported living, where [name of organisation] provides me with support to live the best life I can, but before that I had experienced some bereavements. When I was [age], my girlfriend committed suicide. She was hanging from a bunkbed, and that was the start of my troubles, really. I started to have behaviour that they said at the time was not right, not normal. I became aggressive and used to kick off—that is the term they used—quite a lot. Before that, I had had a stable upbringing by my mum.

There was one time when I went to bed as I do normally, and the police came. Quite a lot of policemen came, and they handcuffed me. I had never been in prison or been handcuffed before, but they handcuffed me and pushed me to the ground because they said I was being violent and I was a danger to myself. With the type of learning disabilities and other disabilities that I had, there are certain trigger points. They pinned me to the ground and took me off. When they charged into my bedroom, my reaction was to fight back and I became violent towards the police officers, but I did not know what was going on. No one told me. No one told me they were coming. No one told me why.

I associate being handcuffed with doing something wrong, but I did not think I had done anything wrong. I ended up in what I can only describe as a room with nothing in it. It was a white room with nothing in it, just white, and a little hatch they passed things through. What was strange about it was that I started the evening at home wearing clothes and I

ended the evening not wearing any clothes, just wearing a white thing. They took my clothes off and took the change I had in my pocket, my watch and everything.

I was trying to fight back, fight it, fight these people. I did not know where I was. I later found out that it was an ATU about 30 miles from my home called [name of institution]. I did not know where my mum was. The next thing I knew, they were saying, "You need to take this medication. You need to take it now". I asked, "How can I take the medication if I still have the handcuffs on?" They took off the handcuffs, they made me take it and I fell asleep. I assume that whatever I had made me drowsy and I fell asleep.

Chair: Basically, did the way they came to detain you make you worse?

Witness A: Yes. I did not know what was happening. Looking back at it now, it does not feel real. It feels like some sort of nightmare. It was not a safe place. It was not a treatment room. I got no assessment or treatment done. There was no care. I was just put in this room, and I lay there and went to sleep. How can you put drugs in people like that? I do not understand that part of it and I still do not.

If I look at the care, support and treatment that I receive now, it is like being in a different world compared to what they did. I do not have any regrets in my life. I try not to, but I have disappointments. One of the disappointments I have, and one of the nightmares I have when I go to sleep at night, is the look on my mum's face and the scream she let out when these people came in to take her son away.

Q2 **Baroness Lawrence of Clarendon:** How did the staff treat you while you were in detention, and was there anything that upset you about your treatment?

Witness B: Yes. They restrained me by using a hand against me. They would hold it and twist it in places it should not go. They threw me into my cells and it hurt. I was not allowed to go to the bathroom when I wanted, so I had to ring a bell to let them know. Sometimes they would answer it but sometimes they did not. This made me feel uncomfortable and upset. I really did not like it. It denied us our basic human needs.

Baroness Lawrence of Clarendon: How was it for you?

Witness A: It was like a prison. Actually, I went to a prison a while ago as part of a previous job to help support some inmates who were suffering from mental ill health. They had TVs and PlayStations, things that they could do. There was nothing like that where I was. Like Witness B said, you had to ask permission to go to the toilet or go outside. That was the worst thing.

I still have trouble now with small spaces. As can happen when someone is in a small space, I started to hear voices and see things that were not real. I do not know whether that was the medication, but I do not think I saw any lights or fresh air in the year I was there; I do not think I went

outside. I knew the behaviour I was told I was expressing was considered bad.

I can now go and get my food whenever I like, because my human rights have been put back in place. Being in that room was like being in a box. When I went in there for the first time, a little bit of me died that day.

Baroness Lawrence of Clarendon: Can you say a little about the staff and their treatment of you?

Witness A: They all wore the same uniform, white coats. They did not listen to me. They did not look at me. They did not ask whether I was okay. They said, "You are going to take this now"; "You are going to eat this now"; "You are going to drink this now". When I used to question why, they just said, "Because we are telling you to". When I used to get aggressive, the same thing happened. They handcuffed me and pushed me down to the floor like I was a criminal.

Baroness Lawrence of Clarendon: Witness B, how did the staff treat you?

Witness B: It was not very good. I did not like the staff. They were horrible. They left me with bruises on my arms and legs. The attitude towards people with learning disabilities stunk. They just did not want to know. They did not give you a date for when you could be discharged. They did not give you a date for when you could leave or go out to get some fresh air. It was just horrible. It was just uncomfortable.

Q3 **Fiona Bruce:** Good afternoon, again. I am going to ask about your lives now. Witness B, you told us a little already. You told us that you are married and that you have brought up four stepchildren, which is quite an achievement in itself.

Witness B: Yes, it is.

Fiona Bruce: Can you tell us a bit more about your life now?

Witness B: It is a lot better now than it was back then. I do my own things. I can go out on my own. I am independent. I have my own money. I go out and get shopping, cook my own food, take the dog for a walk, that sort of thing. It is really good now. I am really enjoying life.

Fiona Bruce: Are you coping well?

Witness B: I am coping well. My medication and my mental health are kept well under control by my doctors, so they keep an eye on me. If I am feeling depressed or anything, I will go to the doctors and ask them to change the medication where needed. It is good.

Fiona Bruce: It is great to hear. Thank you, that is very helpful. Witness A, you have given us some really great descriptions of the life you had when you were detained. You told us you are now in supported living and you get good care and support. Could you tell us more about your life now and have you cope?

Witness A: I feel like I have been given a second chance, really. I have a job. I play football; I love football.

Fiona Bruce: What position do you play?

Witness A: Striker. I do not score many goals at the moment, so I am under pressure.

Fiona Bruce: I know the feeling. I have a son like that.

Witness A: I live with two housemates. I have a job. Before, I just about existed, but today I can tell you that I now live my life the way I want to, with my support staff who treat me like a human being. That is all I have ever wanted, and that is all people with learning disabilities and/or autism want: to be treated equally, like everyone else.

Fiona Bruce: What is your job?

Witness A: I work for [name of organisation] […], helping people with learning disabilities and autism […] to live the lives that they want to.

Fiona Bruce: That is quite something. Thank you.

Q4 **Chair:** We have heard about the lives you live now and the situation when you were detained. In your opinion—I will start with you, Witness A, and then ask you, Witness B—was there any benefit, any plus side, to you being detained in that way? Are you different now from how you were then, which meant that they needed to detain you, or was it just a very bad episode that you think should never have happened and that caused you to suffer?

Do you think there was any justification for it? Do you think they were right at all to detain you? Were they completely wrong, so you were the same as you are, sitting here now; it is just that they were doing the wrong thing to you?

Witness A: No, I should never have been detained, absolutely not. If the steps had been taken that are available now, I would have had the right care, treatment and support. I can only speak for myself, but someone like me should never, ever have gone into a place like that. As I said earlier, I put on my forms that I do not have a criminal record. I have never been in prison, but to me that was my prison.

Chair: Witness B, was it necessary for you to be detained?

Witness B: I got into trouble. I broke the law, so I should have been in prison or somewhere just to secure me, to get my mental health under control, but the ones I was in I should not have been in. I did not like them. It just did not feel right. I felt I should be with my family, but I was sent away from my family, so I had no family support. I had nobody at the time, so I do not think I should have been in that hospital; I should have been nearer home.

Chair: Witness B just mentioned her family. Witness A, you mentioned your mum. When you were detained, how did that work out? You were living with your mum when you were taken off.

Witness A: Yes. They burst into my mum's house at [time] at night and said, "We are taking your son". Mum was powerless to stop them. She did not know why. She did not understand, I do not think, the brute force of

it all. I can hear her screaming even now. That stays with you. That triggered off my mental health and my suicide attempts later on in life.
I would argue strongly that my need for support now may be partly due to what happened; I do not know. My mum was not even allowed to visit me. Why not? They do not tell you. They strip things away from you and you become less human in places like that.
There are pros and cons to any medication. I am on medication now, but at least I understand why I am on medication. At least someone is telling me why certain things are happening in my life. Back then, there was nothing, like I was a criminal, like I had done something wrong. I was locked up. I remember the keys jangling, the turning of the lock and the shutter coming down.

Q5 **Lord Woolf:** I would like you to help us with this, if you can. You have had good times and bad times. The bad times came and were then followed by better times. Do you know of other people who have been treated badly, and can you tell me whether that worried you? Would you like to answer first, Witness A?

Witness A: I have friends who have been sectioned and, like Witness B, are now married, have children and have wonderful lives. I have friends who are still in units and should not be. You will hear later on stories of other people who should not be in ATUs or secure units, in my opinion. If you can give the right support, it is usually just enough.

Lord Woolf: Witness B, could you help me on the same thing? Do you get upset?

Witness B: It makes me angry and upset. I want to get them out. It is not fair seeing them stuck in hospital for years and years and not being able to get out. They should be out, enjoying life, getting married and having a great life. It was not easy for me to be in a hospital for three years, so I do not think it is great for people to be in hospital for years and years and years.

Lord Woolf: Can you tell me also, Witness B, whether there are things you believe could be done to stop these wrong events happening?

Witness B: Inspections are really important. They get them out into the community and get them the right support that they need. Train the staff so they can better communicate and deal with people in these hospitals. It was not easy to come out of hospital for me. Having suitable housing and beds so they have somewhere safe to stay is important. More support in the community is important, too.

Lord Woolf: What about you, Witness A? What do you think should be done to ensure that people are all dealt with properly? One of you mentioned inspectors, did you?

Witness A: Yes. Care and treatment reviews take place in ATUs and similar settings now. They are usually done by people with lived experience of those situations. For me, it comes down to training of staff, the right funding, really implementing the Care Act and really making

sure these horror situations do not happen to people, and they do not spend all their lives in what I call prisons. You only have to look at the success stories for me and Witness B, and what we can achieve when you promote our human rights and give us a chance.

Lord Woolf: Thank you very much. Those are the questions I wanted to ask.

Chair: Thank you very much indeed. I hope you feel that, after what you wrongly suffered, you are at least helping us make the right recommendations and understand what it is like to be in a situation where you have fewer rights than if you had committed a criminal offence. You have done a very good and helpful public service by coming along and speaking to us. We will think very, very carefully about what you have said and include it in our report. Thank you very much indeed.

Examination of Witness

Paul Scarrott, My Life, My Choice

Q6 **Chair:** Hello, Paul. Welcome. Thank you to Andy for coming along to support Paul. As I said when we met earlier, we are really grateful to you for coming along and talking about your experience to us, because we are the Joint Committee on Human Rights, which means we are concerned about everybody's human rights. That is the approach that we take. Half of us are Members of the House of Lords and half of us are Members of the House of Commons.

Really, we just want to hear about your experience. There are no right or wrong answers on this; we just want to hear your experience, because we are going to write a report at the end of our inquiry, and it is very important that we hear from you about your experience.

I will ask the first question and then a number of other questions will be asked. My first question is to help us understand the situation. How did you come to be detained? Did you know why you were detained? Did you think it was right thing to happen to you, that you should be detained in that situation?

Paul Scarrott: It was something that happened in my past. It was something I did. It gave me flashbacks, what happened in my past. For the safety of me, my girlfriend at the time and the public, I went to try to get some help. I took tablets. The only problem was that I thought no one was listening to me because I had flashbacks to what happened in my past.

After that, I ended up in hospital, and there the mental health team came and spoke to me. The psychiatrist introduced himself and explained to me: "We cannot get you into a unit at the moment". He said, "We will not

section you. We will keep an eye on you. Could you please stay safe with our support?" I said yes and stayed safe. "When we find a bed, we will get you into a unit. If you carry on with what you are doing, you will be sent to Dundee. You will be sectioned and you will have nothing". I said, "Okay". The people around me supported me all the time until I went in voluntarily. I did not go under mental health. I volunteered and went to the unit in Oxford. That is where I went for treatment.

Chair: Doreen is going to ask you about what happened when you were in there.

Q7 **Baroness Lawrence of Clarendon:** How did the staff treat you while you were in detention? Did anything upset you about the treatment you received?

Paul Scarrott: The staff treated me okay. They were really supportive. When I went in voluntarily, they shut the door behind me and I knew it was locked. I knew I was safe, because the window was open. The staff were very good. The only place was the room and the area was dull. It was old fashioned, dark and everything. They treated me okay, but I do not think they treated some of the patients very well.

I had a nurse who assisted, a person called Chris Jones and Dr Dermott, who was my psychiatrist. They really helped me very well. Sadly, neither Chris nor Dermott are around any more. They really supported me very well. I had to go one to one with a nurse to the place to have therapy treatment, come back and that kind of stuff. A couple of the staff really were good. I could not sleep at night because of all the flashbacks I was having, so they said, "Okay, Paul, we have set a little computer up", a laptop or something. "You can go on the laptop and play games. When you are ready, you can go to bed", and that was it.

Baroness Lawrence of Clarendon: That is good. You had really good treatment and a good experience from the staff when you were in for treatment.

Paul Scarrott: Yes.

Baroness Lawrence of Clarendon: That is very positive.

Chair: I am going to ask Fiona to ask a question, but I have to warn you that the bells will be ringing soon and it is not a fire alarm. It is just that we have to vote, so those of us who are MPs from the House of Commons will, I am afraid, have to break the evidence. We will go down and vote, and then come back and carry on asking you questions.

Paul Scarrott: That is fair enough.

Q8 **Fiona Bruce:** Good afternoon, Paul. Thank you for coming to talk to us. I would like to ask you about your life now. You are not in detention now; you live an independent life. Could you describe it to us?

Paul Scarrott: Not being big headed, I am really well and really good, because I belong to a charity and I am doing a lot of stuff for the charity. Let me get my bit of paperwork out. I am on the Oxfordshire transforming

care board. My colleague behind, who you spoke to earlier, and I do CTRs, care and treatment reviews, going out to different places and finding experience, and CQC work. We run a nightclub for our disability group. I am part of the Thames Valley Police board meeting. I am out there doing a lot of stuff.

Fiona Bruce: Absolutely.

Paul Scarrott: I am married. My wife and I are married, living in our own flat and everything.

I found this charity, My Life My Choice. I could not go back to a full-time job after I came out of treatment, because if I went back to full-time work, since I get benefits, it might make me relapse again. I found the charity My Life My Choice through an organisation helping me to find it. Not being funny, but now I will not turn back time. I am going forward. I like charity working and helping other people in the community.

Fiona Bruce: You are making a real different to a lot of other people's lives.

Paul Scarrott: Yes.

Chair: Do I take that to mean, Paul, that you are saying that, with the right support, the right accommodation, and the right ability to work but not too much, you can lead a good life but all that is critical to you leading that life?

Paul Scarrott: Yes.

Q9 **Chair:** Do you think there are other people in detention who could be leading that sort of life if they had good support? Is the key thing support outside?

Paul Scarrott: Yes. I have been to a lot of places for care and treatment reviews. I have spoken to people, and a lot of them talk about red tape and Section 64, or something, under criminal justice laws. I spoke to a guy in one unit somewhere a long time ago, and he was there when he was 18 and now he is nearly 40 or 50, but he is still under criminal justice. They said they could not get him out or anything, because they have no support and criminal justice is causing the problem. I have seen people in units for a long, long time. When the evidence is put in front of us, we see how many times they have been moved around. There is not enough support from the Government or the council, all that lot, to get them out of the unit.

With the Winterbourne View scandal and what went on, when we first found out we tried hard to get the law and everything changed. We hear it all the time. Sometimes I go in there and come out upset, because people have been in there for a long time. Luckily, staff where I work support us and they are trying to get things done. There are too many people in units away from their family.

Another time that I went to a unit, there was a guy living in Southampton and his mum lived on the Isle of Wight, and was travelling to see him. They would not pay her travel expenses. She was in her 80s or 90s, and

travelling from the Isle of Wight is quite difficult. A lot of places are too far away. I would like to get people back, if they are under criminal justice, not too close to where they live, but somewhere close to their family if their family is still supporting them.

Chair: Paul, it is going to take us about half an hour now to vote. You have given such a good description of the right support, as an alternative to the difficulties of detention and what have you described as wasted lives, that you have probably helped our Committee enough with your evidence for us to say that you can sit back now and listen to the next witnesses when we come back. Is there something that you want to say that you have not had time to say to us?

Paul Scarrott: If I think of anything, I will decide when you come back.

Chair: Okay, while we are voting, you can decide whether there is anything in particular that you wanted to say that we have not asked you about. Otherwise, we will go on to the next people, but you will be here anyway. We are going to vote. We are going to run, otherwise we are going to miss it. Thank you.

The Committee suspended for a Division in the Commons.

Q10 **Chair:** Paul, thank you very much for your patience and for bearing with us while we were voting. Fortunately, we do not have any more votes, but thanks for waiting. I would like to ask you to conclude the information you are giving to us with any other points that you think will help us with our inquiry about detention, how people are detained, how they are treated when they are in detention and whether it is necessary.

Paul Scarrott: There were two items I missed out. When I was in the unit, I would ask for female nurses to look after me, because I was not comfortable with male company, blokes' company, because of what happened in the past. I told them I wanted female nurses. They said, "Fair enough", and that was good support that I had. Some people who go into units do not get to choose what staff they want. They do not get the right choice of staff. One person I went to see a long time ago said, "I just do not want to hang around with female nurses", but they would not listen to him at all.

There was another point. I could go out with a member of staff if I wanted to. Sometimes, when I was in a unit, I did not have privacy. I could not have privacy in some places. They would come in and say, "Do this, do that". If I wanted to do something in private, they would not let me. They would watch me.

Although I went in voluntarily, they did not tell me, "You can leave any time". They said, "You are in here until you have finished treatment". They did not say, "You have the right to go out. If you want to finish this, you can go". They did not say that. When I went in, I thought I would be in there for a long time until they told me I was leaving. I find a lot of people saying that. That is my evidence to you guys.

Chair: Basically a lot of people do not know how long they are going to be in there and how they will get out.

Paul Scarrott: If you go in voluntarily, that is fair enough. If you go in under the Mental Health Act, people will not know how long your treatment is going to be. One guy said it was like prison life; you are sent to prison. That is what some people think. Some people say that you go in and come out. That is fair enough; you get six or seven months' treatment. Some people I have witnessed have been in there longer and they said, "It was like a prison sentence to me". They did not go in due to mental health issues, although some others did. That is why I fear that some people are in there longer than they should be.

Chair: Thanks very much for your help with our inquiry, Paul. You are welcome to sit in the public part while we hear from our next witnesses.

Examination of Witnesses

Julie Newcombe and Jeremy.

Q11 **Chair:** Thank you very much indeed, Julie and Jeremy, for coming to help us with this inquiry. As I explained earlier, we are the Joint Committee on Human Rights, so our perspective is the human rights of every individual and, in particular, the issue of those who are detained and whether their human rights are respected in detention. Half of us are Members of the House of Commons and half of us are Members of the House of Lords. At the end of hearing from a number of witnesses, we will write a report with recommendations in it and send you a copy of the report, so that you will know what we have taken from your evidence and how it has fed into our recommendations.

I will just ask you to explain to us your involvement in this situation. You are both parents, so what are the circumstances that you have come to talk to us about?

Jeremy: My daughter is in St Andrew's Hospital in Northampton. She will have been there for two years next Thursday, and the majority of that time has been spent secluded, locked in a cell, with no treatment and no therapy.

Chair: How did she come to be in that situation, and do you think it is the right decision for her? What say has she had in it, and what say have you had in it? Is this a good thing that you are explaining, or is it bad, and if so, why?

Jeremy: Bethany is autistic. Her part of the spectrum means that she cannot cope with situations that cause her anxiety. When she becomes anxious, her natural response, in the way her brain has formed, is either

to try to escape that situation—flight—or, denied that, to attempt to fight. It is the fight-or-flight response.

Bethany has been through 17 failed placements, which did not understand that part of Beth's condition. That ended with Beth becoming criminalised, as these organisations failed to cope with her challenging behaviour. We were told that, to protect Beth and to protect other people, Beth needed to enter an ATU for assessment and treatment. ATUs are full of very distressed people, so Beth witnessed self-harm, she heard screaming, she heard people distressed and shouting. With Bethany's condition, she has massive sensory issues. She cannot cope with that environment. I am neurotypical and I could not cope with that situation, so Beth was unable to survive in that environment without resorting to fight or flight.

Their answer to that was to lock Bethany away. When I visited Beth I knelt down at a hatch in the door six inches square and talked to my daughter through that hatch, the hatch they feed her through. That is the hardest thing I have ever had to do and there is no need for it. If the right people are doing the right things around Bethany, you would not know that Bethany has autism. She is the most wonderful, engaging, funny child you would meet.

Bethany had an assessment this week from a potential provider. That provider took Bethany to a farm where she mucked out horses and played with hamsters. When Bethany was returned to the unit, they did not have sufficient trained staff available to enable her to stay out of being secluded, so they put her back in a room and they locked the door. In that room Beth has no privacy. They watch Bethany showering and going to the toilet. I cannot imagine how my daughter copes with that situation. I am six foot four, built like a brick wall and strong, but I am not as strong as Bethany and never will be. It is cruel. I have reports that state that her treatment is inhuman. I will share those reports with you.

Chair: Thank you very much.

Julie Newcombe: I am recovering from that. My son has been out of hospital now for three years. When he was detained under the Mental Health Act, he spent 19 months in five different in-patient settings, one after the other. He kept being rocked on to the next one, because they did not know what to do to help him. Since he has been out, I have been supporting other families a lot and hope to bring their perspective to you today as well. I have campaigned and been part of the Rightful Lives online exhibition, which explores the human rights of people with learning disabilities and autism. Basically, because I am so horrified by what has happened to us and is still happening to so many other families, I felt the need to carry on doing something about it.

My son is called Jamie. He was originally detained under the Mental Health Act as a result of some medication changes and some inappropriate behaviour management, which was essentially punitive. If he had a bad day and did something inappropriate, he was told he could not go out. If you know Jamie, a day inside is a failed, lost and wasted

day for him. He needs to be out and about, doing things. To say to him, "You cannot go out", is the ultimate punishment, and of course it resulted in him panicking and fighting, because he was just in meltdown.

Once he was detained, our local authority gave notice to his provider, which effectively rendered him homeless. He was detained under the Mental Health Act, and even if a tribunal had wanted to discharge him it would not have been able to because there was nowhere for him to go. We see that so often. The power of tribunals is diminished because there is nowhere for the person to be discharged to.

In addition, we agreed to him going into hospital, partly because we did not have much of a clue what it was all about, but also because we were promised it was only going to be for a few weeks. They would sort out his medication, he would have some care and treatment, then he would be able to come out again and be all sorted out. Of course, a few weeks turned into 19 horrific months.

Chair: Are you saying, Jeremy, that it starts off with Bethany failing to get the support she needs and then her being in a place that is inappropriate, which makes her suffer and then makes her worse?

Jeremy: Absolutely. A child with my daughter's sensory issues is placed in a seclusion cell, which is a horrific environment anyway. She then witnesses another person in distress carried past her by a group of staff, with that person kicking, screaming, shouting and crying. The sensory overload that that creates is torture for my daughter. It is absolute, utter torture.

When Beth witnesses and experiences that, her anxieties trigger and she becomes upset. She wants to fly or fight but cannot. That leads to more and more restrictive environments, so they remove anything for Bethany to do from the room. Not only is she shut in an unsuitable environment, but her activities are restricted. What can you do with a child through a little square hole in the door?

Chair: Julie, was it the same for Jamie, in your view? Did the failure to give him the right support and treatment at the outset lead to him being in the wrong place, where he suffered, which made him worse?

Julie Newcombe: Yes, it definitely did. The example I can give you is that, while he was in all these hospitals struggling to cope with the environment and the distress of other parents, I was able to visit and take him out under Section 17 leave. In the morning in the hospital, he would be restrained or in seclusion. In the afternoon, I would take him out into the community by myself. We would go to Costa, to a farm, on a train ride, doing all the things he loved, and we never had a single problem in all that time, because he was doing things that interested him and kept him fulfilled. He would go back to the hospital and the problems would start again.

Q12 **Baroness Hamwee:** I am struck by one thing that both of you have said. Jeremy, you said that there had been 17 failed placements, and I think you, Julie, said there had been five

different settings. Was there the same problem with each of them successively? In Beth's case, was it the sensory overload? I am searching for the right word, but if I use the word "facility", do not assume any judgment as to whether it was a good or bad facility. Was the difficulty the same in each of them before they gave up on her?

Jeremy: First, we struggled to get the correct diagnosis for Beth. We achieved a diagnosis at one point that was then not recognised by social services. That led to them, instead of placing her in units that were particular to her part of the spectrum, placing her in units that dealt with general autism, which is about putting boundaries and constraints in place.

That is the exact opposite of what you do to a child with my daughter's condition, which is pathological demand avoidance. She is hardwired to avoid people making demands of her. She does not understand why I, as a father, could say, "Beth, have a shower". Where do I get that power from? She does not understand that. That causes anxiety, which leads to meltdowns.

Without staff who understand that and who are trained, none of these placements was ever going to fill Bethany's needs. She would become frustrated. She could not communicate at the level she needed to. Anxiety leads to challenging behaviour, and she very quickly learned that, if you escalate challenging behaviour, often police officers are called. The police officers sit on you. She likes that as an autistic child, because it is deep pressure. In the same way we love a hug, that fulfilled one of Beth's needs. They would then put her in a police car and take her away from the situation. That is what Beth wants. If you are put in a police cell, you are safe. Your parents come and that is a bonus. You are fed, given hot chocolate and looked after. We teach Beth and people like Beth that that is a way of avoiding anxieties, and they become criminalised because of that.

If you have the right people doing the right thing—distracting, diverting, offering choices instead of placing demands—this will be negated. The potential placement does not have a seclusion room. It does not need one, because there are properly trained staff. In 25 years, they have never called the police, never.

Baroness Hamwee: Did a similar failure of diagnosis keep Jamie moving?

Julie Newcombe: No, his diagnosis is known. When he was first detained, he was sent to a psychiatric intensive care unit, which is possibly the worst kind of environment for someone with autism to be in, because it is for very unwell people. You have to remember that Jamie functions emotionally as a four year-old, possibly. You have just locked up a child, effectively, even though he is in a man's body. You have locked

him up in an environment with a lot of distressed people and, sadly, with staff who do not really understand how to care for him.
In fact, I would go as far as to say that some of the other patients looked after my son better than some of the staff did. He was in two PICUs altogether, one ATU and two locked rehab units. He was shipped from one to the other because they did not know what to do with him, so they passed him on to somebody else.
I would like to offer to the Committee the Mental Health Act code of practice chapter 20, which I think will support both Jeremy's and my evidence. Paragraph 20 says, "Compulsory treatment in a hospital setting is rarely likely to be helpful for a person with autism". That is statutory guidance. It also says, "If people with autism do need to be detained … it is important that they are treated in a setting appropriate to their social and communication needs", and, "Practitioners working with or detaining people with autism should have relevant specialist training and experience". It says, "People with autism should be detained for as short a period as possible". As I said, that is statutory guidance and it is routinely ignored.

Q13 **Jeremy Lefroy:** Thank you for sharing this. We really appreciate it. Could I follow up on what Julie was saying? Why do you think it is routinely ignored?

Julie Newcombe: It is because they can get away with ignoring it. There is no accountability in the system whatsoever. At one of the PICUs, I asked the manager if she would make reasonable adjustments for Jamie because he has autism, and she said, "I am not going to". I said, "It is a legal requirement", and she said, "I can't. I am not going to". How do you hold people accountable for that? There is nowhere for you to go and get help from. There is no support. You are there with your child and you have to put up with decisions like that.

Jeremy Lefroy: When she said, "I can't", why was that?

Julie Newcombe: She did not offer an explanation. I expect it was because it is very difficult to accommodate a person with autism in a PICU. It was the wrong place for him in the first place, but that is where he was put.

Jeremy Lefroy: For both of you, in any of the circumstances in which your children were restrained or isolated, even for a short time, would you have said it was ever necessary? Was it always unnecessary, but just easier to do it?

Julie Newcombe: I would say it is easier. It is easier to restrain. It is easier to seclude. It is easier to medicate. We also need to remember that one of the big solutions in these places is to pump people full of drugs so that they are completely sedated and will not be a problem to the staff. It is service driven, not person driven.

Chair: Do you think the guidance that you have read out bears no relation to your experience?

Julie Newcombe: No, none whatsoever.

Chair: Is that the same for you, Jeremy?

Jeremy: Yes, absolutely. There is no alternative environment in the hospital for Beth. She is identified as not being able to cope on the ward. The only other place they have is seclusion. St Andrew's stated 18 months ago that it had completed its assessments and that Bethany did not need in-patient care, but nothing has changed. They wrote a document that explained exactly what Bethany needs. It is brilliant; it nails exactly what she needs.

Jeremy Lefroy: What does it say she needs?

Jeremy: She needs a therapeutic environment that is based in the community, surrounded by people who understand her needs and who can meet those needs, where she has access to things such as animals. They provide such a benefit to her. Stroking pets is a calming mechanism.

Chair: Somewhere, the system gets this and clocks it, but the reality is just a cruel parody and completely different.

Jeremy: Yes, absolutely. We know what she needs, but she cannot have it, because under the Mental Health Act we put risk assessments in place that prevent her from accessing what she needs. We cannot bring animals into the seclusion cell, because that is not what we do under the Mental Health Act. Beth needs to be somewhere safe where she does not have access to things, even though they are therapeutic things.

Q14 **Fiona Bruce:** My questions are for Julie and they are both about the present day. The Committee is seeking to understand what your son's life is like nowadays, and what your life is like now.

Julie Newcombe: What is his life like now? We are still undoing the damage. As I said, he has been out for three years. He put on a whole lot of weight in there, several stone. He has not been diagnosed, but he probably has some kind of post-traumatic stress disorder. His behaviour has become incredibly obsessive. He cannot make decisions. He will even hold out two sweets and ask me, "Which one shall I eat?" He has been completely damaged by his experience.

You have to remember, if I may backtrack a bit, that while he was in hospital he had no help with his personal care. His clothing went missing. His possessions went missing. Even some money went missing. I gave him some money so he could phone me, but it went missing. He was forced to wear other people's clothes, including their underwear.

When he was transferred from one setting to another, he was locked in a cage in the back of a van. When we got to our destination, because I was following in my car, the driver and escort did not know exactly where he was going, so they wandered off to find the exact ward that Jamie needed to be admitted to. I was left with my son distressed, in a cage in the back of a van, and I fed him sweets through the bars of the cage to try to calm him down.

His belongings went into hospital in a nice suitcase. Some of them emerged in black bin bags. There were other people's clothes in those black bin bags. I found his toothbrush in a trainer. Some really personal notes from another patient had somehow found their way into Jamie's black bin bag. Hospitals are so quick to tell you about confidentiality and patient privacy, but they put somebody else's personal notes in with Jamie's possessions.

At one point he had no access to hot water for three weeks. He was given nuts, even though he has a nut allergy, and then he had his EpiPen administered unnecessarily. Considering he has had heart surgery, that was a pretty dangerous thing to do. He was left alone for long periods when he was supposed to be on one-to-one, sometimes two-to-one, observations. He was subjected to a police interview, although he clearly lacked capacity even to understand the reading of his rights, and we had to fight to get the police to come to the hospital to interview him rather than him being dragged off to the police station.

He had his arm broken in a restraint, the right humerus bone. His arm was wrenched up behind his back until the bone snapped. He was then not taken to accident and emergency for 24 hours, even though his arm was completely swollen. I have a picture of the X-ray if you want to see it. That is the X-ray of the bone and that is Jamie in a sling, because the hospital broke his arm.

We think his life was put at risk by medication changes that were really dangerous. I went to visit him one day and he could hardly stand up. He was so overmedicated it took him 40 minutes to tell me what he had had for lunch. As a reaction to that, he was taken off the maximum dose of a highly addictive benzodiazepine over three days, which is dangerous. We were told by the responsible clinician that it was safe. When Jamie started having minor fits as a result of the withdrawal, I took a video of it and gave it to the responsible clinician, who told me it was nothing to worry about. Think about somebody going through all those things—violence, abuse, other things that happened to him in these places—for 19 months. When he comes out, he is not just going to carry on as normal. Forget that. He was damaged. He still is damaged and it is three years later.

Fiona Bruce: How is he living today?

Julie Newcombe: He is living. He has a flat that is in a residential home. It is a registered home split into flats for people who need that bit of extra space. He is lucky; he has the top floor. We call it the penthouse suite, so he is on the top floor there. He has a core staff team who are brilliant. The manager of the home is brilliant. They really get him and know what he needs to do. They know he needs to be out and about, so he gets to go out. He has completed a course in a special needs college. That is him celebrating his graduation. He now does voluntary work on allotments and on a community farm, so he is making a contribution.

The key is the right environment, the right staff, as Jeremy says, and the right activities so that somebody can live a really meaningful life. It is not difficult and it is probably cheaper.

Fiona Bruce: That is really good to hear. What issues are you still facing in terms of the need for support?

Julie Newcombe: The issue we are still facing is that, although he is out of hospital, he is still not home. He still lives some distance from us, and if the traffic is bad it takes me about an hour and a half to get there to visit him. Typically it is an hour. He is still not home. He is still not living in his home community, close to his family and the place he grew up, with people he knows.

We still have to complete the job. It is only half done. We are lucky; he has a very good community mental health team. We are working with them to undo the damage. The organisation that cares for him has some good in-house behaviour analysts, who are also helping with that. We have a long way to go. We have to get him home and we have to get him better, but the way we are doing it is to try to make as many good memories as we can and blot out the bad ones.

Q15 **Lord Trimble:** You gave us a very interesting description of what your children have gone through, but what has it been like for you as parents?

Jeremy: It has been horrific: the inability to hug your child, because she is locked away from you; seeing your child on antipsychotic medication, even though she has no diagnosis of psychosis. You hear that Bethany has been assaulted by staff. She put her hand through the hatch and fiddled with the door handle, and because the handover to an agency member of staff was not sufficient they did not know that and they repeatedly struck her. There have been sleepless nights and worry as a parent, a feeling of utter failure as a parent.

Like I said, she is stronger than me. It has destroyed the family. Beth has lost two close members of the family, who have not seen her for two years. I cannot imagine a worse situation to be in as a parent, and there is no need for it.

Chair: Did you feel that the system was drawing on your experience and understanding of her situation and engaging with you?

Jeremy: Where has my parent voice been? I am the expert on my daughter. Two months ago, I had to fight to be included in what they called a professionals' meeting. I am the professional about my daughter. Bethany has no voice. That is clearly identified, but as a parent I know the things that are left out of reports. I know the positives; I know the wonderful things that my daughter can do. They are not in the reports. The people who read those reports see a condition and not a person. They do not see a child. They see legislation that they have to meet. They lost the person a long time ago. They lost my daughter.

Julie Newcombe: I agree. "Horrific" is a very good word. You are scared. Nobody has a GCSE in the Mental Health Act. You suddenly have to do a whole load of learning and you are excluded at every opportunity. I can remember going to one meeting when 20 professionals had had their professionals' pre-meeting, like they do, and made all the decisions without me even being there.

I was allowed to go in afterwards, sit and listen to their decision, which was actually to recommend a move to St Andrew's. I spoke through clenched teeth with tears pouring down my face: "He's not going to St Andrew's. People die there", so we managed to avoid it, luckily, and he was shipped off somewhere else, where they just broke his arm.

It is so scary. You are constantly fighting and it takes over your lives. I would spend the morning researching, doing emails or whatever, and the afternoon visiting Jamie. In the evening I would do his personal care, because the staff would not do it, and I would read him his bedtime story. I am one of the lucky ones, because I could do that. We found his new home ourselves, and then had a bit of a fight to get him discharged to it, but it was our efforts that found the place where he is living now.

The hospitals like to punish parents if they speak out, and they have a clever way of doing that. They will take away Section 17 leave and restrict your visits, so do not speak out, because that is what will happen to you, as it did to us. At one point, we were threatened with transfer to a secure hospital a long way away, because we were causing trouble. We were denigrated to other professionals orally and in writing, and we were repeatedly accused of lying. Nobody should have to go through that, especially when it is their child.

Chair: If you feel okay about it, where there is anything in the papers you have that reflects the attitude to you as parents and that you want to share with us to help us understand, we would be grateful to see it.

Julie Newcombe: We will send that to you.

Chair: The bottom line is to ensure that you as parents do not have to see your children suffering, but also that the system benefits from your knowledge, expertise, love and care, which are great resources. We would be very interested to see how the system relates to you as parents, as David's question suggested.

Q16 **Baroness Lawrence of Clarendon:** My question is to you, Jeremy. I think you answered most of it already when talking about your daughter and what it has been like for you. In your view, why is your daughter still in detention?

Jeremy: There is a lack of community placements and a failure of transforming care. In a meeting on Monday, a telephone conference with Children's Commissioner Anne Longfield, questions were asked to identify potential placements for Beth to move to, and commissioners were talking of options next summer and the end of next summer, because there is no

availability. There must be provision for our children. Local authorities have no option, they say, but to place our children in these units.
They also love the fact that, when they place our children in these units, they are no longer paying the bill. My daughter's care in St Andrew's is approaching £15,000 a week. That is an awful lot of money, the best part of £800,000 a year or £1.6 million so far. A cash-strapped local authority does not want that bill. Actually, it would not cost them that much. There could be a massive saving. It has cost £1.6 million; it is a 100-bed unit. That is £80 million a year for one venue alone.
What would services such as CAMHS—child and adolescent mental health services—GPs and social services be able to do with that amount of money in the way of training and preventing our children going into these units in the first place? The money is going into the wrong part of the system. It is not going into prevention; it is going into the very top, when the failures have happened, and there is nothing else to do with our children but lock them away. That must be reversed. It must.

Baroness Lawrence of Clarendon: It sounds as if it is more beneficial for St Andrew's to keep your daughter there.

Jeremy: They are putting a horrific amount of money into their back pocket to provide seclusion, no therapies, no treatment and no exit strategy. Where is their incentive?

Baroness Lawrence of Clarendon: How long has Beth been in the assessment unit now?

Jeremy: It will be two years next Thursday, and 18 months since they admitted that they had completed their assessment.

Baroness Lawrence of Clarendon: How far away from your home is that?

Jeremy: It is just short of 70 miles. I am lucky that I drive. It can take me an hour and three quarters. Mum, however, does not drive, and to get there by public transport, have contact and return home takes a day.

Baroness Lawrence of Clarendon: How far away is mum?

Jeremy: She is a little further than I am. We have been far farther away in the past. Beth has been in in-patient units in Cardiff and Preston. You arrive, and because they do not have the staff to treat her she is in meltdown and they go, "I am sorry, you cannot come in". You have to turn round and go home, knowing that your child is waiting for you.

Baroness Lawrence of Clarendon: One of the things I read is that, when you see Beth, you have to be down on your knees to look through and talk to her. What is she like when she sees you and you can see each other face to face?

Jeremy: It is brilliant. It has been hard in a way, because to visit your child in that situation and tell her your good news is like rubbing her nose in it: "Look at what I've been doing". You say to Beth, "What have you done today?", but that is the wrong question to ask. Because of the media campaign I have been involved in, people have sent greeting cards and gifts to her, and she really looks forward to that. But for a child in a unit

there are no experiences to talk about. There is nothing good in Beth's world, shut in seclusion. Put yourself in her position.

Baroness Lawrence of Clarendon: One of the things was about when she was taken out and she went to a farm. Was that the only time that happened or has it happened again since?

Jeremy: That only happened on Tuesday of this week.

Baroness Lawrence of Clarendon: That is the first time it has happened in the past two years.

Jeremy: There is nothing in the care plans to repeat that at the moment. It was only because there was a properly equipped and staffed provider who could facilitate that.

Q17 **Chair:** The Government have given repeated assurances that they want to reduce the number of young people and children who are detained in this way. Is it your view that Jamie and Bethany continue to be detained because of a more generalised problem and that this is why the numbers are not coming down? Do you feel that what happened to Bethany was a one-off terrible abuse of her human rights or a generic problem that is in the system?

Jeremy: It is a generic problem. I have been in communication with people since the media and Twitter campaign that I have taken part in. I was horrified to find out the numbers. There are hundreds of young people in these units, and so many of those parents have been gagged by courts to stop them talking. Walsall local authority attempted to place a reporting restriction on me, because it saw what I was doing as infringing Beth's rights to privacy.

This related to a Radio 4 documentary that I was involved in talking about Beth. I asked why they did not bring Radio 4 into that court. It was just me as the parent. I believe the answer was that they did not have a case they thought their lawyers could take on, against the might of the BBC's lawyers. I am aware of so many other parents who have been gagged, who cannot speak out. I am aware of so many other people who do not have parents. They have no voice.

Chair: Do you think the scale is not clear and properly acknowledged?

Jeremy: Absolutely.

Q18 **Ms Karen Buck:** I have been struck, listening to your evidence, by how lonely the experience you have both gone through sounds.

Jeremy, you just started to answer one of the questions I was going to ask you. What has been your experience of having representation or advocacy through this, or legal challenge at any stage, or using an official complaints procedure at any stage? Has that happened? Obviously if it was a legal challenge you would have been legally represented, but have you had advocacy and representation on behalf of your children through these processes?

Jeremy: I have never been offered advocacy for myself. We had to fight tooth and nail to get an advocate in place for Bethany. She struggled to engage with ones the local authority offered, because either there were communication issues or Beth just did not engage with the personality.
We identified a particular advocate who Bethany had had contact with, through support mum had found, and we very much wanted that advocate for Beth. They had spoken on Skype and they were getting on so well. It was added to part of Beth's care order that, should Walsall fail to engage an advocate for Bethany, the advocate we named would be engaged. Walsall objected to that on the grounds that, because the advocate had worked with mum, she could not then advocate for Beth, because there was no independence.
Actually, that is a judgment for an advocate to make and not a local authority, and that decision was being made by an independent reviewing officer who just happened to be the ex-team leader of the social services children's department. Who was he to talk about independence? We had to fight. It has only been since early this year that we have had an advocate from the Children's Society, who has worked with Beth.

Ms Karen Buck: Have both young people had legal representation on their own behalf?

Julie Newcombe: It fluctuated depending on which hospital Jamie was in. In one hospital, he had a fairly decent solicitor. In another hospital, he had a fairly decent advocate, but it was pretty random as to whether they were available or effective. I was never offered an advocate or any kind of support, and my local authority did not give me much either.

Ms Karen Buck: Did either of you use the official complaints procedures, at any stage?

Julie Newcombe: You do not have time. Well, I did not. You do not have time to do that. You are just trying to keep your head above water. We wrote a letter of complaint to the first PICU, where they lost all his stuff, and they gave us a few quid as compensation. As I said, you are just keeping your head above water and trying to keep things right for your child. You do not have time to go through official complaints procedures and do that sort of thing. It is impossible.

Jeremy: You are not offered any guidance on your rights to complain or the avenue to complain through. I complained numerous times to Walsall children's services reviewing officer, in her role as corporate parent. She would copy me into emails and letters written to St Andrew's on our behalf and on their behalf. Walsall was not happy with what has happened to Beth. They got absolutely nowhere. I utilised the services of my own MP but, again, got nowhere. You are banging your head against the brick wall that is the Mental Health Act.

Chair: Was there any internal investigation into the breaking of his arm, besides you complaining? What happened after that? Was anybody disciplined? Was there any rewriting of the rules? Was there an apology? It is quite a serious thing to have an arm broken.

Julie Newcombe: The person who did it was suspended immediately and later dismissed from his job. I do not recall ever getting an apology. Safeguarding was carried out by the local authority where the hospital is, and it concluded that breaking that bone was an unfortunate accident. We have since complained about the ineffectiveness of the safeguarding, because that was no accident.

We received some reassurances that they were changing the way they were doing things, that they were more effective now, that the person who did the safeguarding does not work for them any more, and that sort of thing, but it always feels like it is you against them, everywhere. It is you against the hospital, you against the local authority, you against the commissioners. It is just you, the parent, trying to fight for your child.

Baroness Lawrence of Clarendon: That bit I understand. This situation is quite lonely, because you have to be the voice for your child and speak up, since they do not have a voice. You are put in that position. I understand when you say that you do not have the time to put in a complaint. That itself takes time to do, but all you are trying to do is to keep your child safe and to make sure that he gets whatever he or she needs.

It is hard, and I can relate to that, because you are fighting the system. The system is always stacked against you. They have the law, the advocates and everything in place to prevent you supporting your child. I just want to say to you that I understand all that and how the system is always stacked against you.

Julie Newcombe: Thank you. May I take this opportunity to say this? This is quite interesting, because Jamie came out of hospital just after Building the Right Support was announced by NHS England. He has been out all the time Building the Right Support has been operational, and I have spent that time supporting other families and campaigning, as I said earlier. I have some quotes from other families, if you would like to hear them.

Chair: We definitely would. Thank you.

Julie Newcombe: They are: "Seeing my little boy only just 13 years old, and mentally aged five, slumped in a chair falling in and out of sleep, while I wipe the drool from his chin. I will forever have nightmares of seeing such distress"; "He was in a comatose state, unable to stand or sit up straight, or string a sentence together, for four days"; "He hates PRN, because it makes him feel awful for days, so he won't ask for it"; "He was kept on medication because the staff couldn't manage his behaviour. They just did not have the skills due to limited training and he put on loads of weight".

There are examples of physical abuse: "His arm was broken in three places. He has had black eyes, wrist burns and bruises all over his body. Carpet burns have taken the skin off his face and chin"; "The hospital called to say they were taking my son for an X-ray for a lump on his chest. It turned out to be a broken clavicle bone and the injury had

actually occurred several weeks earlier"; "He has started banging his head in frustration and I can see how hyper-alert he is to the staff who have used restraint on him"; "He has lost so much weight in there. His primary nurse said they were not concerned. He told me he was scared, because he was not getting any food and he thought they were never going to feed him again"; "Whenever I visited, he smelt awful. He was not washed or shaved and his nails were ridiculously long. He often wore someone else's clothes, and they were always dirty".

"My son was kept in seclusion for up to nine hours at a time. The rule was that he could not leave until he was quiet. With his anxiety and sensory presentation, there was no way this was possible. He started to bang his head against the wall and would bite the wood in the doorframe out of desperation"; "One hospital punished my son for displaying stimming behaviours by stopping Section 17 leave"; "My son had to earn home leave by cleaning wards"; "He was left on his own in his flat. Staff would not go in there. Food and medication were passed through a window and he had to shout out if he wanted a drink or some toilet roll. Staff did not always come".

Q19 **Chair:** Thank you very much indeed for coming and talking to us about this situation. You have described the reality for us in very graphic terms, so I appreciate what it must have been like for you to come and explain it to us.

Jeremy: As we are talking about people's rights and equality, may I take this time to read a statement issued this week by the Equality and Human Rights Commission? This was written by Rebecca Hilsenrath, the chief executive; the Equality and Human Rights Commission is supporting legal action. "Bethany is living and being treated in shocking and inhumane conditions. She has just the same rights as anyone else—she has the right to good-quality health care, she has the right to dignity and she has the right to respect. She has, extraordinarily, been kept under lock and key for two years because of repeated failures by Walsall Council, St Andrew's Hospital, Walsall Clinical Commissioning Group and the NHS to arrange support for her. She is just a daughter who needs to live near her family, as independently as possible, and this needs to happen now. The Human Rights Act and the Equality Act are there to protect people like Bethany, and it was immensely important to us to help her and her family in this case".

Chair: Thank you both very much indeed. We have to conclude now. Julie, do you have one final point to make?

Julie Newcombe: There was a question about why people are not being discharged from hospital, and I have an awful lot of thoughts on that, but I will summarise them for you. Perhaps we could speak at another time. The slow rate at which people are being discharged from hospital is for financial reasons. The transforming care millions are not ring-fenced or audited. Not all the TCPs got the money they applied for in their original

plans. The private sector owns half the beds. There is a huge conflict of interest for any responsible clinician who knows that heads on beds are going to pay his salary. They are owned by investment companies or venture capitalists, profit driven with low costs, offshore holding companies and vested interests.

The other financial things that really irritate parents are the silo budgeting, which Jeremy mentioned earlier, and a complete lack of up-front ring-fenced community funding, which is needed to get these people out of hospitals. There are commissioning issues. Commissioners do not challenge hospitals enough, either on the reasons for detention or on the standards of care that they are paying for. They do not always know what they are paying for and they are often funding abuse.

There is little new or creative thinking at local level to provide personalised housing and care solutions, a lack of accountability throughout the system and insufficient intervention by the CQC. CTRs, which were the big flagship thing about transforming care, routinely do not get done properly, or if they are the recommendations are not followed up. They just get put in a drawer in cyberspace.

There is no personalisation in the system. There is a failure to see the people behind the pie charts. Psychiatry is an issue. Why would care and support for people who do not have a mental health condition be led by psychiatry? It should be nurse led, it should be therapy led, it should be psychology led. There is an overreliance on medication that people frequently do not need.

Too many of the responsible clinicians working with people with autism and learning difficulties have a forensic background; they do not have the necessary training in autism. They do not listen enough to the people with autism and learning disabilities, and they do not listen to their families and supporters. They are risk averse, keen to assess the risk of doing something, but failing to see the risk of not doing it. Thank you.

Chair: Thank you very much indeed. You have both told us very openly about your personal circumstances, but have obviously built up, the hard way, a lot of expertise and understanding about the system and how it works. That will help us with our inquiry, so thank you very much indeed, and all the best to you.