HOUSE OF COMMONS

Health and Social Care Committee

Oral evidence: Treatment of autistic people and individuals with learning disabilities, HC 1195

Tuesday 13 April 2021

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Watch the meeting

Members present: Jeremy Hunt (Chair); Rosie Cooper; Dr James Davies; Dr Luke Evans; Barbara Keeley; Taiwo Owatemi; Sarah Owen; Dean Russell; Laura Trott.

Questions 49 - 116

Witnesses

I: Dr Ian Davidson, Autism Lead, Royal College of Psychiatrists; Dr Ken Courtenay, Chair, Royal College of Psychiatrists Intellectual Disability Faculty; and Ian Birrell, Journalist.

II: Sir Norman Lamb, former Minister at the Department of Health; Baroness Sheila Hollins, Founder, Beyond Words; Dr Theresa Joyce, Clinical Psychologist, and formerly National Professional Adviser on Learning Disabilities, Care Quality Commission; and Professor Philip Fennell, Emeritus Professor, Cardiff University.

Examination of witnesses

Witnesses: Dr Davidson, Dr Courtenay and Ian Birrell.

Q49 **Chair:** Welcome to the House of Commons Health and Social Care Committee evidence session on the treatment of autistic people and those with learning disabilities.

We have two expert panels this morning. I want to move straight to the first panel. We are delighted to welcome Dr Ian Davidson, who leads on autism for the Royal College of Psychiatrists; Dr Ken Courtenay, who chairs the college's Intellectual Disability Faculty; and Ian Birrell, a journalist who has campaigned on issues around the treatment of autistic people and those with learning disabilities for many years. Thank you very much for joining us.

If I may, I want to cut straight to the chase with Ian Birrell. You cut to the chase in your writing a lot, so you won't mind me doing the same with you. Recently, you wrote a deeply disturbing story about a 16-year-old girl. You used the name Susie, although that is not her real name. You described her NHS care as "shameful" and little improved from the old Bedlam asylums. Why?

Ian Birrell: I guess the one change from Bedlam is that people do not pay to see this; it is actually hidden away out of sight of society. I have covered, through my work as a foreign correspondent, some of the worst things that humankind can do to one another, yet few things have distressed me as much as seeing what is going on within our own health system.

I am the parent of a daughter with learning disabilities. I had heard about these cases, but I had never quite understood the full horror of it and what was really going on until I spoke to Jeremy, the father of a girl called Beth. Beth was 17; she was a teenager who liked to be outside. She liked animals and music, and yet for 21 months she had been locked up, mainly in solitary confinement. She had only a foam mattress. She had nothing to do all day. She was watched and monitored by guards. She was fed through a hatch like a wild animal, like a dangerous creature. Her father told me that, when going to visit her, it was like the scene in "The Silence of the Lambs" when the FBI person played by Jodie Foster walks down a long corridor with cells on either side. He would have to kneel down to talk to his daughter.

What was the crime that this girl had committed? The only thing was that she had autism, and she lived in a society that did not provide adequate community care. Therefore, due to these failures, when she hit distress, as many people with autism do in their teens and in adolescence, she ended up in that hellhole run by a private company, a charity. She ended up in a hellhole that made her condition worse. It was not helping her.

We know that, with something like autism, being held in those circumstances—perhaps with the noise of a mental health institution or in

solitary confinement, and treated in that disrespectful way—makes their condition much worse. Indeed, in Belgium I even met someone who was permitted to have legalised euthanasia because of the mental distress that she had suffered as an autistic teenager within a similar system of what is laughably called care.

I wrote the story and it led to questions in Parliament. I then got inundated with letters, emails and calls from other families in the same situation, whose lives had been torn apart and whose children were being destroyed by what is called care. I remember there was one in particular, who also made the Hannibal Lector analogy, called Adele Green. She told me about her son. He was called Eddie. He had gone from being a fun-loving, sporty kid. She had sought help; she had trusted the doctors. The doctors said, "Let us put him in an ATU for a month and we'll look after him and get him better." She went to see him a month later and he was a drooling, shambling wreck. He had put on weight like Beth, who had grown obese. He had been heavily sedated. He could barely recognise her or talk to her.

Adele said to me very quietly, in words I will never forget, that when she saw him she thought she had failed as a parent because she had failed her son. The difference between the two children I have just told you about is that Beth has now got out because of the publicity over her campaign. Her father withstood a gagging order, incredibly, from the local authorities that sought to silence him from talking publicly about his daughter's plight. She is now enjoying life, showing that, with good care, people with even severe autism and learning disabilities can live a happy and fulfilling life.

Eddie, however, is still in hell all these years later. I think it is seven years later. He is still locked up. The month's treatment that was supposed to get him right and set him on the path back to living a fulfilling life has actually just been a slipway into hell. These cases are so common, and it is happening in the name of healthcare.

Q50 **Chair:** How many people are in the situation of Beth or Eddie at the moment, or at any one time?

Ian Birrell: According to the official figures, there are about 2,200, although others would quibble with that and say it is about double that. The question is, why is anyone in this sort of care? It is not care at all; it is making things worse.

Q51 **Chair:** We will come to the solutions in a moment. You know the NHS incredibly well. You know that it is full of the most extraordinarily caring and well-meaning people, not just the clinicians but the managers who have chosen to spend their lives in healthcare. Even people in local authority systems are very well meaning. How is it that such well-meaning people can allow this kind of thing to happen under their noses?

Ian Birrell: I think it is systemic failure. It goes back to the fact that there isn't community provision. People just want to solve the problem, and they pass it on, and we have silos. There is a systemic system of failure. We have a mental health system that has become far more risk averse. It has become far more reliant on restraint, with the numbers soaring. It has become far more reliant on sectioning and the detention of people. We have rates twice as high as Ireland. We have rates that have quadrupled since the mental health legislation was passed. The whole system is geared towards this.

Unfortunately, it is also a system that, once you are incarcerated in it, (a) it is very difficult to get out; (b) it makes your condition worse if you are autistic; and (c) there are perverse incentives for debt-funded private equity-funded operators to keep people in the system; indeed, some of the experts are also a part of that perverse incentivised system. They have a stake in keeping people inside the system.

Unfortunately, when you have that sort of system, it leads to abuse. It dehumanises people. Ultimately, I think the problem is that we have a society that does not respect people with autism and people with learning disabilities. From the basis of not respecting them and not seeing them as fully paid-up members of society or fully humanised people, that lack of respect leads to systemic failure and the situation with thousands of individuals having their lives wrecked, and families broken and torn apart by the very system that is meant to care, support and help them. Indeed, it involves a lot of terrific people.

Equally, we have seen and we know, from so many other cases of good practice, that it does not have to be like this. There is a systemic failure, and it is not helping people. Actually, people are far more productive, far better off, far happier and far better cared for with proper support in their community.

Q52 **Chair:** Should we follow what they have done in Italy with the Trieste model and ban new in-patient admissions for non-forensic patients?

Ian Birrell: I have to say that my mind was blown when I went to Trieste. I was very struck by the words of one psychiatrist I spoke to before going, who was not a massive ideological fan of the Trieste system. He said that if he was ever mentally ill he would want to be treated in Trieste, and when I went there I saw why. It is for the very simple reason that it is a system based on the rights of the people who need the help.

It is a system based on respect. It doesn't have restraint. The psychiatrist in charge said that in 41 years he had never once used restraint. How can we have a system in Trieste that does not use restraint and a system in Britain that relies on incarceration and restraint?

The one thing I would say is that in Italy it is fantastic for mental health—personally, I would emulate it at the drop of a hat because it is cheaper,

more effective, more efficient, more respectful and better—but there is an issue in that provision for people with learning disabilities and autism is not good in a lot of areas. Just like the care in the community experiment that we had in this country, these things only work if there is proper finance and proper money given to care in the community, which actually delivers the care and support in the community that stops people getting into crisis.

Q53 **Chair:** Lots of colleagues want to ask you questions, Ian, but before that I want to bring in Dr Ian Davidson and Dr Ken Courtenay from the Royal College of Psychiatrists. I want to be completely up front with you. We brought you in because we want to find out whether the RCP has fundamental objections to the Trieste model, or whether you sympathise with what Ian has said. We want to try to expose that debate before we come to our conclusions in our report.

Let me start with Dr Davidson, who leads for the royal college on autism. What is your reaction to Ian Birrell's comments?

Dr Davidson: There were a lot of points that Ian covered. There are absolutely some people who are having very bad experiences, and that is tragic. As he rightly says, that is something that has to be eliminated.

On the specific point about Trieste, wearing my mental health hat as well as an autism hat—as Ian said, it is more about mental health in Trieste than autism—many of the fundamentals of the Trieste model are ones that we fully endorse. When the asylums closed in England for mental health back in the 1980s and 1990s, they were the principles that were meant to be adopted.

However, the big difference in England is that the money did not flow into the community, whereas in Trieste it was very successful because all the money that was in the asylums has been retained in the community. That is a fundamental difference between Trieste and England.

Wearing one of my other hats, Getting It Right First Time, they very much espouse the principle of getting it right first time. There are very front-end assessments. Multiple skilled people do assessments at the front end. They have a very easy-in, easy-out system. There is no wrong front door. Although they do not admit people to asylums, they do admit people to beds. They have beds in every one of their health centres and they admit people to them on an easy-in, easy-out basis. The average length of stay is 14 days. The average length of stay in a mental health unit in England is 32 days. The big difference is that they do not have a big, long tail of people who are in for many months. There are huge benefits to that system.

In the long-term plan for the NHS for the mental health bit, we are trying to increase community services so that we can do more front-end work and therefore prevent people reaching that stage.

Q54 **Chair:** Thank you; that is really helpful. On the Trieste model, the way

they made that change was to make it illegal to admit new in-patients to the old asylums that they had. We have not done that here, but is that the way we could provoke that change and force investment in community provision?

Dr Davidson: That did not work in the rest of Italy. As I say, one of the things to understand about Trieste is that they do not ban admissions. Admissions are very easy in Trieste. You can get in quickly and get out quickly without all the bureaucracy that we have in England around admissions. They have very much simplified the process. It is very much in the local community centre. Some people go to the university psychiatric services as well. They have not banned admissions. They have made admissions much more like what we are trying to do. There has to be a very clear reason for admission and a very focused admission. They get done what needs to be done quickly and get the person back out quickly. That is very much the direction of travel we are going in.

Where they tried to ban admissions and then did not invest in community in some other parts of Italy, it has not worked so well because people are on the streets and other things. We do not want to go down that route.

Q55 **Chair:** Thank you. Let me bring in Dr Courtenay for the learning disability angle.

Dr Courtenay: Thank you, Chair. Ian's account was very distressing to hear.

What I like about the Trieste model is its emphasis on community services and community support. As Ian has already said, there are beds built into the model itself, but how you actually manage the beds is very important. For us, particularly in the faculty, we support the development of community services. The truth is that, if you have beds, in some ways you weaken community services. If you do not have beds, in that way you will actually strengthen community services. I have seen this myself in my own service back in 2009, when we had five beds but we managed to close them because we did not need them.

What we did in that case was to use that resource and put it into a community-based clinical service, in the form of the intensive support team, a multidisciplinary team that was based in the community and was flexible in responding to the needs of patients. What we actually managed to achieve was a reduction of in-patient admissions over the following years down to single figures per year. That was very important. We managed to keep people in the community, in their homes with their families, and when they went into hospital we also followed them into hospital to facilitate their discharge back into the community.

It is very important that we develop community services, as Ian keeps saying, but I do not think we have done that in this country. Until we actually do that and have commitment from everybody to have good, strong community services, we will continue to be in these situations.

With the deinstitutionalisation that happened in this country, people were moved into the community, but the capacity was not there in the community to support them. That capacity is very important. It is about direct care staff, people in supported living homes and people in family homes supporting people, but also professional staff as well. As a result of that, we closed one form of institution and opened up more institutions, which were the hospitals around the country.

As Ian says, it can be very difficult, once someone goes into hospital, to get them out. What is essential in terms of admissions to hospital—whether NHS provision or the independent sector—is that they have to be actively managed. I think the reason why people spend a long time in hospital is that they are not being managed. The admission is not being managed. The in-patient pathway into hospital and the pathway out of hospital is not being managed as it should be. It should be managed by the community services, not just the in-patient services. That is essential.

Q56 **Chair:** Thank you. I will bring in my colleague Barbara Keeley next, but first we will go back to Ian Birrell for his comments on what he has just heard.

Ian Birrell: The key point with Trieste was that they basically ended the distinction between psychiatric illness and physical illness. They said, "We are not going to have a separate hospital system, because it is based on rights and respect. It is based on empowerment of the patients." It has worked quite well in some other parts of Italy. I do not quite agree that it has not worked. It has been very bad in some parts, but in other parts it has worked quite well.

I slightly query that there is this great drive towards a more humane system. If there are all these efforts, why has restraint gone up so hugely in Britain? Why has sectioning gone up so hugely in Britain? We have a system that has total lack of community provision, and because of that it is reliant on risk aversion. We use risk aversion models, which studies have shown are between 18% and 76% accurate. People are being detained on the basis of something that may only be 18% accurate. Is that just?

There is a famous quote, I think by Bismarck: "Better to free 10 guilty men than lock up one innocent man." We are locking up hundreds and hundreds of innocent people on the basis of models that are flawed, and on the basis of a process that is totally dehumanising. Ultimately, it is about empowering patients, families, people with autism and people with learning disabilities so that everything is driven by their needs and not by the diktats of the bureaucrats deciding how the money should be spent, or indeed, dare I say, the doctors who think they know best but actually, in the case of psychiatry, have been party to some of the abusive practices that have gone on.

Q57 **Barbara Keeley:** Ian, you have done some great work investigating these issues. You talked about the circumstances of Beth, and I was very

moved by her case. As you know, I have spoken about it many times in the House of Commons, and about other people too, but it is such an exemplar of what can go wrong that it is a good case to talk about.

You have also looked at what is underpinning this. What we want to do in this Committee session is get to the bottom of what is going wrong and try to point out how we might change it. I know that you have investigated the funding situation. In this session we are talking about community resources, but we know that is underfunded. In fact, I talked to Jeremy—Beth's father—when she was held in the way that you talked about. He had heard from the local authority that they said, "We need a breathing space in funding such an expensive case." They colluded in what happened to Beth because they needed a breathing space in funding the hundreds of thousands that it was costing.

Could you tell us a bit more about that? It is important that we get to the bottom of what is going on with the funding of places in in-patient units.

Ian Birrell: Certainly, funding is part of the equation. I do not think it is just about money. I think money is clearly a factor, and it is a big factor in community provision, which has been hollowed out over the last decade. There are also profound issues that we need to ask about why we are paying so much money. I am not against private medicine. I have always argued that it has a role to play in the NHS, but within the mental health system there are some very poor private operators who have grown very fat on the back of it, often based in tax havens abroad. They are making a lot of money through private equity and opaque ownership systems. We have to ask why we have a system that is wrecking people's lives. Those companies, with very bad records, continue to have people sent into them.

Ultimately, why is it right to send one person with autism or learning disabilities into what is effectively an abusive form of imprisonment, purely because we do not have the care system in place to support them in the community? There would be outrage if it was any other minority, yet this has carried on. We see the horror stories that occasionally erupt, at Winterbourne View, Whorlton Hall or whatever—I have exposed others—and yet it carries on. It should be rooted in the basis that no one should be sent somewhere that is unsuitable and makes their condition and their life worse. That should be the very basis, and then all the money should flow.

Yes, there would need to be some double funding set up for community provision, to transfer people out of the system and back in. Beth also shows what happens when you get it right. She is today a happy teenager, purely because she had a father who was able and strong enough to fight off a system that, at every turn, was trying to thwart him in getting the best and most decent care for his child, his daughter.

There are a lot of other issues behind a lot of the autism stuff. We have a system that is very late to diagnose autism, particularly in girls where it

was less recognised historically. We need far more money and effort put into early diagnosis of autism. In a lot of cases the autism is not diagnosed until the girls hit crisis. Girls tend to go inwards when they hit adolescence and have a crisis. They harm themselves or have eating disorders, or whatever. I think that behind a lot of the rise in eating disorders and self-harming is the issue of autism being undetected.

Boys might become more aggressive. We know that the prison system is partly filled with people who have learning disabilities and autism. If we can only detect it earlier, and then put in place the community provision to support people, it would make it less of a fight. I know from my own experience, with a much less complicated family story, that you end up fighting the system. This is not right. The system is meant to support people. It is not meant to be a battleground. Yet we have a system that ends up abusing people and breaking families. That should be the starting point for everything. That should be the starting point for every commissioner who is pushing this on to someone else's budget, away from the local authority budget into the health budget. It should be the view of every doctor involved. It should be the view of everyone. Why is this person being sent into detention?

Q58 **Barbara Keeley:** I have some questions for Ian Davidson and Ken Courtenay. Dr Davidson, it is important to get the scale of what we are talking about. Earlier, you said you were sorry that "some" people were having bad experiences. We are talking about 2,000 people, that we know of, who are in that situation. We are not talking about five, 10 or 25 people; we are talking about thousands, and it may be more than 2,000, as Ian Birrell said.

Neither autism nor learning disabilities are diseases to be cured or treated. They are functions of diversity. We are in a situation where 73% of people in ATUs apparently need in-patient care according to their care plan. I do not know that we would accept people being in hospital for a physical health condition that could not be cured or treated, and just keeping them there even though they were not getting any sort of treatment for it. Why is it seen as acceptable for people with learning disabilities or autism to be kept in hospital?

Dr Davidson: Apologies if I used the word "some". I actually said "tragic", I think. I have no doubt it is tragic. I said "some", because not all of those 2,000 are in hospital because they have autism or learning disabilities. Some are in mental health units because they have serious mental health problems for which they are being treated. I think it is important to distinguish between those two things.

Coming back to your key question, the royal college has a limited role in this. The royal college is only about the education of psychiatrists, and this is a much wider issue. What we are trying to do is get to the point whereby there is a clear purpose why everyone gets admitted to hospital and why that is essential, and then that what is essential is done as quickly as possible and they get out again, just like in physical health. If

you need to go in, there must be a very clear reason for going in, and you know when you are going in what that reason is. You know what your expected length of stay is going to be, you know what needs to be done while you are in there and you get out quickly. We are moving towards that model, but I have absolutely no hesitation in agreeing with people that we are a long way from that model. We need to boost community services to get to that model.

I also have no doubt that we have to do more work, not just in training people but supporting them. In terms of training them, the Royal College of Psychiatrists would acknowledge that before the 2009 Autism Act it had not really looked at the whole issue of autism as a whole of life, all ages, all abilities issue. Since 2009, it has been catching up. Part of the reason why we have an autism champion—a post created in 2017—was to bring the focus of the whole college on to it and to see that it is an all life, all abilities issue. We managed to get that into the core curriculum last year with the GMC, so it is now part of the integral training.

Q59 **Barbara Keeley:** Let me stop you there for a moment. You have quality standards on learning disabilities and autism. You have mission statements. At the same time, the number of people detained in these units has not fallen significantly in five years. As we know, the use of restrictive practices is rising. Does that mean that what you are trying to do at the royal college is not having the desired effect? If it is not, what else can be done? This Committee needs to understand what can be done. We are looking at a problem that is absolutely stuck. Do you agree that the situation is stuck? What else could be done?

Dr Davidson: I do not entirely agree that the situation is stuck, but I agree that it is moving forward much too slowly.

Q60 **Barbara Keeley:** The numbers have not fallen in five years. That is the key measure. There is no measure of improvement, is there?

Dr Davidson: I am trying to answer that. Sorry if I am not making myself clear.

We have huge progress in the diagnosis of autistic people. There are far more autistic people being diagnosed now than ever. There are still delays, and I do not dispute that. Compared to even 10 years ago, the numbers have hugely increased. That means a lot more people who were always going to go into mental health units with unrecognised autism are still going into those mental health units but it is now recognised. There is a huge variation, in that more and more people are going in who are recognised and are going in for mental health problems.

I do not think the raw numbers on their own give the full answer to the picture in terms of mental health units. There are still far too many people spending far too long in hospital, and that is what we need to work on. If you want, I can give you more details about that outside this, because there is a lot going on about that.

In terms of the training and stuff, yes, we have done a huge amount of training. We are working our way through. We have diagnostic services now for people who do not have learning disabilities and who are not children. We are able now to give more training opportunities about autism to psychiatrists working in other fields so that they can get better at recognising it and get better at doing reasonable adjustments. There is a wide range of things going on. I am not pretending that it is going fast enough. I am not suggesting that.

We know that there are things that can be done in the community. We are pushing, along with NHS England, to get autism hubs set up, so that there are hubs in local communities that people can go to for advice and support. That will bring in integrated care from health and social care, and all sorts of other agencies. Some of those are already up and running. That is a really important step forward to try to get to the point where people do not reach the point where they have deteriorated to needing admission.

I accept that some of the policies in this country are more risk averse than some of the policies in other countries like Italy, which contributes to some of the admissions and some of the length of stay. That is undoubtedly true, but there are things that can be done, and I am happy to discuss the things that can be done because it is really important that we do the things that will work.

Q61 **Barbara Keeley:** Ken Courtenay, it is the same question, but there is a specific issue about assessment and treatment units. Under section 2 of the Mental Health Act, clinicians are supposed to have 28 days to assess patients; 92% of ATU patients have been in a hospital of some sort for more than three months. The average length of stay, when you include transfers, is six years. How long does it take to assess somebody and determine that they need community support?

Dr Courtenay: It can be difficult to say categorically how long it takes to assess somebody. The 28 days is a valuable period of time. However, for people with learning disabilities who may also have autism and perhaps a mental disorder, such as a psychotic or mood disorder, or other issues going on in their lives such as trauma, it can be very difficult to elicit the signs that would go to make up a diagnosis within that period of time. In many cases, that is why people are detained under a treatment order, which will be for treatment but also for further assessment.

The challenge for clinicians—again I come back to this—is the complexity that people present with, because of the issues that are affecting them and their experiences in life. Many clinicians and clinical teams would be working hard to reach a diagnosis in that assessment period. The diagnosis is often made in the community before people are admitted to hospital. There are reasons why people are admitted to hospital. It may simply be that it is not possible to treat them in the community. The resources may not be in the community, or—

Q62 **Barbara Keeley:** We know that they are not, but don't you see the figures that I have quoted to you as a failure? Twenty-eight days would be a long time compared to the Trieste model, but 92% have been there for three months, and the average length of stay is six years. Surely, that is a massive failure of the system.

Dr Courtenay: Absolutely; I agree with you, yes. It keeps coming back to the capacity and the resources to support people in the community. As psychiatrists, we do not support people going into in-patient services unless they really have to. We are doing whatever we can to support people in the community—

Q63 **Barbara Keeley:** But they are there in their thousands, aren't they?

Dr Courtenay: They are. Yes.

Q64 **Barbara Keeley:** Don't you feel that the royal college should be taking more of a stance on this? It should be taking a stronger position on this and using its influence to change things.

Dr Courtenay: Yes, I would agree with you. As Ian has said already, our role is really around educating and supporting our colleagues. Yes, it is a challenge around the royal college in terms of leadership. We can do that. We can do more of it as well.

You quoted some of the items that we have already produced in terms of the equality letter for learning disability and the standards and services. That is just an example of what we have been doing. There are the publications we have written on mental health and intellectual disabilities, and autism as well. We are supporting our colleagues in that. However, it really depends on what level of influence we have, because we are not directly providing services. We are not controlling the systems or the organisations that are providing the care.

Q65 **Chair:** Barbara, could I jump in? Dr Courtenay and Dr Davidson, do you agree that basically they do things better in Trieste than we do in England?

Dr Courtenay: Not necessarily, particularly around the area of intellectual disabilities. I have not seen evidence that would say that the Trieste model is supporting people in a proactive way. From my own experience of visiting Italy, I notice that services are provided more in congregated settings and by specific providers, so—

Q66 **Chair:** What I am specifically talking about, Dr Courtenay, is the easy-in, easy-out system that Ian Birrell and Dr Davidson were describing, where basically they do not have the situation where people are, on average, in in-patient units for six years. They find a way of stopping that happening. You are not prepared to say that that is a better system than we have.

Dr Courtenay: I cannot say that for people with learning disabilities because it may not actually apply. As I said, we do not know clearly what impact it is having on people with learning disabilities in Italy. Going back

to the models here, we have been moving towards community-oriented models. Again, it is about supporting them and having capacity in the community.

Q67 **Chair:** Let me ask Dr Davidson for his view in relation to autistic people.

Dr Davidson: We do not have clear evidence that Trieste has a good model for autism. However, as I said earlier, the model that they are using for mental health, and the principles they are using for that, if they are applied to autistic people, are good principles to apply. There are good, strong community services, easy in, easy out. There is integrated care, and when you need it, you get the support you need on a person-centred basis. That is what we are aiming to achieve in England. I am not saying that we are there. I acknowledged earlier that I realise we are not there. That is the direction of travel we are trying to go in. As a college, we are pushing for that. In our other roles, we are also working with colleagues in the HSE and NHSE to try to achieve it.

That is the direction of travel we are going in: easy-in, easy-out, person-centred care, and only stepping up in intensity when it is appropriate to step up in intensity, which includes using a bed when it is appropriate.

Q68 **Dr Evans:** At danger of repeating some of the issues, the panellists will see that the Committee is very keen to get to the nub of this. I feel that this is very much a principled OSCE question when I ask it.

First of all, Dr Courtenay, is it ever a reasonable position to get someone with learning disabilities as an in-patient in a non-forensic case?

Dr Courtenay: The reasons for admission, in my experience, have been around the level of risk that the person poses to themselves or to their carers. It comes back to the level of risk that the community supports and can tolerate. Some services are able to manage people who are quite risky and keep them in their own environment, whereas others are not able to do that. That will then precipitate an in-patient admission.

Other reasons for admitting people are around clarification of diagnosis, for example, or stabilising people in terms of medication or other therapies, or to conduct assessments that are impossible to do in the community.

Q69 **Dr Evans:** With the danger of putting words in Ian Birrell's mouth, I think he has come out quite strongly in saying that principally it should always be community led first as a guiding light, and there should be no in-patient care.

Leading on from that question, we hear a lot about the cases that go wrong. What about the cases where families need in-patient care? Do you have a feel of the proportion of where that should be? From your principled arguments, it sounds like there is potentially a clinical case for non-forensic admissions. The question therefore asked of your speciality is, at what level should that be, and have we got the proportions right?

Dr Courtenay: I do not think we have. It can be difficult getting people into in-patient services, strange as that might appear. Our threshold for admitting people is perhaps too low. We should certainly be providing extra support in the community before looking at in-patient admissions.

In the practice of psychiatry, our focus is very much on keeping people in the community, working on their strengths and supporting families as well. It does not work well when clinical people are not working alongside families, and supporting families and carers in the community. Often where in-patient services have to step in, it is because the system is not working well.

Q70 **Dr Evans:** Is there data on how well it works for patients? From my clinical background as a GP, I only have anecdotal cases. I saw cases where people did not want to be in in-patient care. There are the battles that we have heard outlined. I also saw cases where families were very happy with the care that was provided, and it was the right place for the individual. I have no feeling or balance as to what that level should be. Are there any figures to say where the college feels that the balance should be set?

You say that we do not have the balance right, but is there a strong proportion of people who say, "Yes, actually, we need that support and that care for families"? We have heard the tragic cases where people are kept in. Is the problem actually getting them out? Where is the balance, and where should it be? That is the principal guiding light that we need for this Committee.

Dr Courtenay: The guiding light is about supporting people in the community. Most families will say that is where they want their care to be provided, not necessarily in in-patient services. The efforts and the thrust of clinical staff is to support families to keep people in the community.

Going back to an earlier point that I made this morning, managing admissions is so important. What is actually missing is management of the admissions. I have proposed to NHS England that in fact we have a thing called a clinical contract, an agreement between community services and in-patient services about the purpose of the admission and what is going to happen in the admission as part of the assessment, for example, that will take place, and also planning the path for discharge. It would be an agreement between community services and in-patient services about what is going to happen while the person is in the in-patient service.

It would clearly outline accountability for the in-patient staff and for the community staff in order to facilitate the discharge pathway back into the community. The community does not always have the capacity to support people, and that is what we need to be bolstering as much as possible.

Q71 **Dr Evans:** Dr Davidson, I was struck by a point you made. I wrote it down. You said that in Italy it was an average stay of 14 days and the UK

32 days. You also said that some people go on for many months. Why do you think that is the case?

Dr Davidson: As Ken said, there are issues about how people are being managed. There has been, to some extent, a risk averse culture, as Ian Birrell said, which is that, once you are in, it seems that the threshold for getting you out goes up because people in the community are anxious about the risk coming back to them.

In the Getting It Right First Time programme we have been looking at this for the whole mental health situation. It is not specifically for autistic people, but we have looked at autistic people as part of it. It is very much about having a very clear purpose for admission, using flow tools like red to green, which is a bit of jargon. I can give you details on that. It is actually about saying, "Is every day of this admission purposeful? Is it achieving what we set out to achieve?", so that the person themselves, the family and the staff all know what you are trying to achieve, whether you are achieving it today and, if not, what is blocking it. Any blocks are identified and addressed early. We are looking to seriously reduce the number of over 90-day stays. That is something we are working actively towards. There are a lot of people who come in for short spells.

In answer to your question about data, one of the problems with data is that unfortunately the NHS is very poor at recording diagnoses across the NHS, particularly secondary diagnoses. It is difficult to say how many people are in who are autistic, or in at any time, as has been said. When we looked in the trust where I work at all the people in a certain unit who had been admitted to mental health beds and had autism as one of their diagnoses, their length of stay was on average shorter than the length of stay for the people who did not have autism. None of them stayed over 90 days.

It can be done. I am not saying it is done well enough or often enough. There are still people out there. Part of the problem with the people who are on these long stays is that it was not got right first time. As Ian Birrell said, we often have diagnostic overshadowing. Autistic people's mental health problems are often just attributed to their autism, so they do not get effective help for their mental health problems early. It is complicated, but there is a range of things, and we know that there are solutions to all of them.

Q72 **Dr Evans:** I appreciate that. Without putting words in your mouth, but trying to summarise what you both seem to have hinted at, the process is looking at the ability for those in the community to be able to care. The failure comes when there is a concern that that is not able to be supported. Therefore, the question would be, should we be putting more support in to help those families, or are the families making the choice to put people in because it is the best case for the family? That seems to be the nub of the issue.

If we are principally saying that there is a correct position to put people

into care and hospitalise non-forensic cases, the question is whether that is right and who it is right for. Should we be having several different options and plans for different families, or should we take a principled position from the very start that no one should be going in unless there is a forensic reason to do so? That is the nub of the question that I think the Committee want to get to the bottom of.

Dr Davidson: Can I come back on that?

Q73 **Dr Evans:** Yes, please. That is a hypothesis. We want you to be as frank as you can to help us balance this out; hence why we are taking the evidence. It is really important for us to get a clear picture of what is going on.

Dr Davidson: One of the really important things is that serious mental illness is a life-changing and potentially severely life-shortening condition. If we say that autistic people who have serious mental illness cannot go into hospital, will we allow non-autistic people with the same condition to go into hospital? That is unlawful discrimination. I think we need to move away from this as forensic or not forensic. If you have a serious mental health problem—I cannot breach confidentiality but I could give you examples—bringing in autistic people in a timely manner to give them the right treatment for serious mental illness has prevented catastrophes in the community. Yes, we can demonstrate that quite easily.

As Ian Birrell said though, we can also identify cases where it has gone wrong; I am not suggesting you cannot. In terms of this, I think it is a false dichotomy; it is a false split to say forensic versus non-forensic. If you need to come into hospital for your diabetes, you should not be blocked from coming into hospital for your diabetes because you are autistic and it is a difficult place to be. You should get the best treatment for you. I think we need to distinguish whether people are coming in purely because they are autistic, in which case that is not something I support. Are people coming in because they are autistic and have a condition that requires them to have hospital treatment, which should be focused and delivered to the highest standard possible and as quickly as possible? Yes, they are. Are some people, when they come in, then finding it very difficult to get out for one reason or another? Yes, they are. We need to address that as well.

There is a range of things. If you go for one answer that fits everything, that is not person-centred care. That is important.

Ian Birrell: Can I come in on that?

Chair: Please do, Ian, and then I want to follow up. Luke, I am going to move on, but I will bring you in on the next panel.

Ian Birrell: Very quickly, one thing you have to understand is that a family may have been thrown into this situation. They are trying to hold down their lives. They are trying to hold down their jobs and keep the

family together. They are struggling with dealing with a child's condition, which can be very complex and challenging for them.

If they then go to someone who says, "Go here to this ATU—assessment and treatment unit—for a short while. They'll sort out your son or your daughter", it sounds great and they believe the experts. The experts say that it is the right place. Having got into the system, these people are often desperate. A daughter may be self-harming badly. A son may be becoming quite aggressive, which is very common in adolescence. Families may be desperate. They trust the experts. The experts say, "Go into this place." They go into a system that is basically geared towards mental health, when these are people who often do not have treatable conditions. Some have mental health conditions, but the vast majority of people have autism. They have learning disabilities. They are different from other people in society, but they are not treatable conditions.

They then go into a system that, by its very nature, often makes those conditions worse. Once they get into the system, the condition spirals out of control. The very act of going into the system makes it harder for them to get out. They are going into a system that is medicalised, when they do not have a treatable condition, and it is one that makes their condition worse.

Q74 **Chair:** Thank you, Ian. Dr Davidson, the discussion we have had so far has been all about community treatment being more appropriate but there being a lack of provision and a lack of investment, so that people end up in in-patient units for longer. There is broad agreement that we need more investment in community provision for all sorts of reasons, including what Ian Birrell just said.

The bit that I do not understand, and I would like your insight on, is the cruelty that Ian Birrell talked about—the cruelty to Beth, the cruelty to Eddie, and the fact that there are in-patient units in today's NHS where people are treated in a totally inhumane way. Ian Birrell made some very strong comments that he thought that was partly linked to them being run by private providers who had a financial incentive to keep people in for longer. I do not think he was saying that was the whole problem.

Could you comment on that cruelty, Dr Davidson? I think that is a rather different issue. Even if we are having to put people in in-patient units because we do not have community provision, we should never be treating people in a cruel way, should we?

Dr Davidson: I cannot comment on individual cases, as you will appreciate. In terms of the general question, obviously we should not be treating anyone cruelly. We should be treating everyone with dignity and respect. I have no doubt, and there is plenty of documented evidence, that some people are not treated with dignity and respect, including some autistic people and some non-autistic people. I appreciate that those numbers may be hundreds or thousands. I don't know—

Q75 **Chair:** Hundreds of thousands of people are not being treated—

Dr Davidson: No; hundreds or thousands.

Chair: Hundreds or thousands. Okay.

Dr Davidson: The figure that was quoted was 2,000. I do not think all of those are in that scenario. I cannot swear to you how many are because, unfortunately, I do not have that data. What we know is that the vast majority of people in mental health units do not stay that long and do not experience those things. We know that restrictive practices have risen, as has detention under the Mental Health Act. We are aware of the need to address that.

The college is working to try to help people address that. We are working to try to achieve it. We are working to get people to better understand autistic people so that there is less chance of this, and that reasonable adjustments are made so that the experience you get is better. We cannot control what other providers do. Whether it is private or the NHS, we cannot tell a business what to do. We cannot tell anyone else what to do. We can say that these are the standards that we expect people to uphold. We do not have the ability to enforce those standards as a college.

Chair: I am going to bring in Dean Russell, then Taiwo, James Davies and Sarah Owen. I want to move on to the second panel around 10.30, so I would be grateful if you could be fairly brief.

Q76 **Dean Russell:** My question is, hopefully, a simple one. We have heard a little bit about the processes, but I want to understand what the methodology is for a lifetime plan for autistic people. My understanding is that there will be certain triggers, symptoms and issues that will happen on a whole range of things. What it feels like, from what I hear, is that the families do not necessarily have much of a say and the individual does not have much of a say. I want to understand whether there is such a thing as a lifetime plan saying, "If this happens and I have to go to in-patient care, how long will I get to choose before I come out? How long will the family get to choose before I come out?", and what the process is. Does that exist?

Dr Davidson: It exists in a patchy way. It is not good enough. We have improved the immediate post-diagnostic support for autistic people. It is better than it was 10 years ago, but long-term post-diagnostic support is still extremely limited. There are things like hospital passports and advance directives that can be done. As Ken alluded to, in learning disabilities we have intensive support teams. In mental health, we have intensive home treatment teams and crisis teams. We are skilling them up to work with autistic people who have mental health problems.

Care planning can be used. In theory, the tools exist. It is actually getting to the point where a plan is meaningful because you can access something when you need it in a timely manner. That is the critical bit.

Q77 **Dean Russell:** I am sorry to interrupt, but I am conscious of the time.

Would you say that having what I would call a compassionate lifetime care plan would make sense? From the point that somebody is diagnosed, be it an autistic person or not, there is a very clear pathway and an agreement with families about how their care should be looked at and what in-patient care should be considered, and that is something that sticks with them throughout their lifetime. Perhaps there is a technology solution. Would that be something that would help the process?

Dr Davidson: What we say is that there should be a strength, needs and aspirations formulation as part of the assessment. We want to move away from empowerment-based language to strengths-based language. We want to look at people's strengths and their needs, but also what they want to achieve in life and how to help them to achieve that. That should be set out at the beginning.

Over time, people's choices vary. People's life experiences vary. What we are saying is that they should have access to reviews through their lifetime when they need them. What you thought you would want as a teenager may not be what you want as a 20-year-old or a 30-year-old. There should be an opportunity for reviewing that. Yes, there should be that sort of formulation. There should be that document that you own; it is your own assessment, you have it and you can share it with anyone that you want to. It should then be supplemented as appropriate, depending on what your needs and aspirations are, with things like hospital passports and other types of tools that can be used for specific circumstances, such as if you reach a crisis point.

Dean Russell: Thank you. If anything like that comes in, it would be really powerful to have compassion at the heart of it. I will finish there, Chair, because I am conscious that other colleagues want to come in.

Q78 **Taiwo Owatemi:** I am particularly interested in the training that is provided to your clinical teams and their staff in in-patient units. We have seen from successive CQC reports that the training provided for clinical teams and their staff means that they do not necessarily have the skills or the resources needed for them to provide adequate care both for autistic patients and for patients with a learning disability. Is that a significant worry that you have, Dr Davidson?

Dr Davidson: It is something that has improved, but it is not where it should be. The college would acknowledge that before 2009 we were not looking at autism as whole of life, all ages and all abilities. It was largely confined to learning disabilities and CAMHS training. We have progressed a lot since then. For example, with the support of the college and Health Education England, we ran, co-produced and co-delivered courses that 1,500 people came to—1,200 of them were psychiatrists—in the last two years. I have co-produced and co-delivered training for the CQC around autism as well. We are beefing up the training that people get, as and when we can get the funding to do it, but there is still a large gap.

Too much of the training that is given is too generic. It is awareness training. It is very generic. You have to focus the training on what the staff will be doing, rather than just national, generic training, which tends not to have the impact. If I am working with the older people team, we need to work with the team and talk about what it is like to be an autistic older person, what their needs are and how they will present. If you are dealing with the CAMHS team, it is a different presentation. We have to tailor the training, and that is not universal at the present time. We are getting there, but it is not universal by any means. It is a long way short.

Q79 **Taiwo Owatemi:** Dr Courtenay, are you able to elaborate on that and provide more information as to what training a provider should be giving and what support should be provided to staff?

Dr Courtenay: In-patient staff in particular have their own clinical training, whether they are nurses or psychologists. You also have non-qualified staff, who provide a lot of direct support to people. I am not making a distinction between qualified and unqualified because I think that ongoing training is essential for all staff in in-patient services, particularly around positive behavioural support. Often the reason why people end up being restrained, for example, or there is excessive use of medication, is that behavioural approaches are not integrated into the care well enough to support people. That is something that needs to be provided by organisations on an ongoing basis, to make sure that old staff as well as new staff continue to enhance their skills in this area. I believe that the CQC should be looking during their inspections of services at the level of the training that is being provided.

Certainly, psychiatrists would definitely support alternatives to using medication, for example. It is essential. Once a person has the skills around being supportive in a behavioural and psychological way, those skills are very transferable to community settings too. The difficulty—

Chair: Sorry, Dr Courtenay, I am going to move on, if I may, because we are running out of time.

Q80 **Dr Davies:** I would like one more go at trying to determine the merits between in-patient care and community-based care. We have established that there needs to be more community-based care, but as a basic guide, Dr Courtenay, what would you say is the current proportion of in-patients with autism and learning disabilities who are inappropriately in those facilities?

Dr Courtenay: I cannot give a definitive answer to that. Having had a look at NHS England's dataset, they estimate that nearly a third of people would benefit from being in other provision, and people are waiting for discharge. The difficulty with discharge is that there are not enough incentives in the system to get people out of hospital once they are in hospital. We need to be moving people out, but what are the levers that we have to actually enable it?

Earlier, Ian was referring to hospitals, particularly in the independent sector, that rely on admissions. We need to be looking at the levers and examining the ones we can use to facilitate discharge for people. In many ways, it is in the interests of a lot of people in the system for people to remain in hospital. I do not agree with that at all. I think we should be moving towards helping people to be discharged, and seeing what incentives we can bring in.

Q81 **Dr Davies:** You have proposed a new role: a learning disability physician. Why do you think that such a role could be useful, or is necessary?

Dr Courtenay: It is based on the model that they have in the Netherlands. It is because of the level of comorbidities that people with intellectual disabilities have. On average, they usually have around 11 comorbid disorders compared with people in the general population, who maybe have five. This is data that has been produced by Professor Kinnear in Glasgow.

Again, it comes back to the word "complexity". People have a lot of disorders occurring at once, and medical staff in hospitals in particular may not necessarily be very au fait or aware of how they present in people with learning disabilities. What we are suggesting is that we have a specialist who is more skilled in working with people with learning disabilities and who understands comorbidity, multimorbidity and complex disorders.

It is my ambition that every trust in the country would have at least one physician, one skilled decision-making doctor within an organisation, who can work with people with learning disabilities and who have physical health problems. They can work with our colleagues, the doctors, and families, as well as the GPs supporting them. If we are able to achieve that, again based on the model that they have in the Netherlands, I suspect that we would avoid hospital admissions. We would reduce the length of stay and provide a better quality of care for people with learning disabilities who have physical health problems, whether they are cardiology problems or renal problems. The most important thing is having a skilled senior doctor supporting hospital staff in managing the complex problems that people have.

Chair: Thank you.

Q82 **Sarah Owen:** This relates to the comments from Ian Birrell. We have talked a lot about investment in community provisions, but what I have heard from parents in Luton is that they feel like they are fighting against that system because all the different organisations do not talk to each other currently. What can be done to ensure that we do not replicate a system that we have for social care or existing mental health support in our community? How can that be co-ordinated?

Dr Courtenay: More integration of services is required. I see it in local services, and children's services in particular. Various agencies see the same people, the same families and the same children. They are not

actually talking to each other. It is a travesty that that is happening. They need to come together so that child development services and CAMHS are working together. Why it is so important to get the intervention in children's services is that children with learning disabilities are going to receive services from adult services later in life. It is absolutely dreadful and, for me, it is awful to see how people have missed out on early intervention and the problems that they present with in adulthood.

Speech and language therapy is one example. People cannot communicate, and are not supported to communicate effectively in childhood, and then in adulthood they present with communication problems. That should not happen at all. We should be investing strongly in children's services and mental health services for children with learning disabilities because they are likely to be in receipt of services for the rest of their lives. We have to do the best we possibly can for them in childhood. Going back to what I said earlier, integrating services is vital.

Dr Davidson: I will give a very quick answer. Autism hubs are essential. We need to develop them. We need to build on them and pool integrated care so that every person who is autistic or their family has one place to go. If they do not know the answer, they will know who does know the answer, and stop people being bounced from service to service.

Chair: Thank you.

Q83 **Laura Trott:** Ian, you have given some very powerful testimony about the tragic consequences of in-patient care in some circumstances. Equally, we have heard that clinical in-patient care admissions may be appropriate, and about the importance of patient-centred care and choice. If you were Secretary of State for the day, what would you do? What specific proposals would you implement?

Ian Birrell: First, I would put a lot more money into early diagnosis. Secondly, I would shift the entire system so that patients and families are empowered and that the decision-making process is led by them so that they are not fighting supposed experts. Thirdly, I would change the mental health legislation. At the moment, for a start, things like autism should not be seen as a mental health diagnosis. Matt Hancock is going to change that, or he says he is. Equally, we have a system whereby involuntary admission only has to be sanctioned every six months under section 3, and every 28 days under section 2. What was impressive about Trieste is that it has to be done weekly. I would make it weekly as well and stop any psychiatrist who has a commercial interest through his employer, and is earning money through keeping someone in the system, from having a say in that decision-making process. I think those three things would make a difference.

Laura Trott: That is incredibly helpful.

Ian Birrell: Ultimately, it all comes down to the fact that these are people who have clinical needs but do not have a treatable condition.

They are being treated and medicalised by a system. It is a systemic failure.

The other thing that was impressive about Trieste was that some of the worst carers, who were abusing, beating and stealing from patients under the institutional system, became fantastically good and sympathetic carers when the system was flipped on its head and, instead of being based on incarceration, was based on empowerment, respect and rights. They became really good. It was not that they were bad people. It was that the system itself made them oppressors of the people who were meant to be being cared for. When the system was flipped so that they recognised the humanity of those people, some of them then became very good. I thought that was an absolutely mind-blowing thing to discover. It was the systemic failure that was leading to the abuse in many cases.

Q84 **Laura Trott:** I would like to go into this in a lot more detail, but we are very pressed for time. I want to ask for clarification. You spoke about patients and families being empowered. In response to my colleague Dean's question earlier, we talked about a 10-year plan. Are there specific proposals that you have for how we can empower patients and families?

Ian Birrell: Some of it is societal. We have a society that does not respect people with learning disabilities and autism. Ultimately, I think they should have the final say on decision making. We need to trust them. Generally, in 99.9% of cases, they want what is best for themselves if they are the patient able to make the decision, or the family wants the best for them. They want the best and they know the best. In many cases, they are the experts, not the people who are said to be the experts. Listen to them and let them lead it. As long as the finance follows, we will end up with a cheaper system because it does not cost £13,000 a week to support someone, even with two or three-to-one support, in the community. If we trust the patients and trust the families, and let the money follow their lead in the decision-making process—obviously with a system of checks and balances—we would end up with a cheaper and better system that was not abusing and torturing people, as we do at the moment.

Chair: Thank you very much indeed. It is time to move on to our second panel, but I want to thank our first panellists. Ian Birrell, without prejudging what our report says, I think you are one of our very best campaigning journalists. You have helped lots of people, including myself and many others, to understand the issues. Thank you for joining us.

Thank you, Dr Davidson and Dr Courtenay, for your very open and reflective evidence, which will give us a lot to think about. We really appreciate you sparing the time this morning.

Examination of witnesses

Witnesses: Sir Norman Lamb, Baroness Hollins, Dr Joyce and Professor Fennell.

Q85 **Chair:** On our second panel we have Sir Norman Lamb, with whom I was greatly privileged to work on these issues when we were both Ministers at the Department of Health. We had an excellent working relationship. He has continued to demonstrate his commitment to mental health issues by becoming the chair of South London and Maudsley mental health trust, which is what he now does, among other responsibilities. It is very nice to see you, Norman.

We also have Baroness Sheila Hollins, who is a professor of the psychiatry of learning disability and was previously president of the Royal College of Psychiatrists. She is the founder of Beyond Words and has a son with a learning disability. It is very nice to see you, Baroness Hollins.

Dr Theresa Joyce is a former CQC inspector. She is also a clinical psychologist and has worked in her own in-patient unit for autistic people, precisely the types of units that we have been discussing today. Professor Phil Fennell is a mental health law professor at Cardiff University. I hope he will help us to understand how changes to the law might help resolve some of these issues. Thank you all very much for joining us.

I want to start, if I might, with Sir Norman Lamb. I think you would probably say, Norman, that you have scars on your back from trying to move patients into the community after dealing with the Winterbourne View issue, which became a scandal shortly after we both became Ministers. What is your assessment of why it is taking so long to sort out these issues?

Sir Norman Lamb: We tried to pull off a revolution in the care of people with learning disability and people who are autistic. Ultimately, we did not pull it off. We made some progress but not nearly enough. There was a concordat. All of the key organisations—NHS England, local authorities through the Local Government Association, the Royal College of Psychiatrists and so on—signed up to commit to delivering it, and yet it failed. In a way, it is the failure of a voluntary system to deliver results.

When we started, we were in a very difficult position. We had no data. No data was collected on who was in the institutions, so I felt like I was operating in a fog. We are not in a better position. We introduced the collection of data, so we can now track this, but it is a massive failure of commissioning. I know that Viv Cooper, when she came to give evidence to you, made that point.

Commissioners are not trained. There are no standards for commissioning. The document "Transforming Care" called for the pooling of budgets. It said that should be the default position, bringing local authority budgets together with NHS budgets in a locality so that money could flow with patients out of hospital and into the community. That has not happened. It is a shocking failure.

A related point is that the failure of successive Governments to reform and inject more resources into social care holds us back. Most people with learning disability, and autistic people, are still supported through social care—local government. Yet, it depends on very poorly paid people. Often their personal budgets have been trimmed right back. When a crisis happens, there isn't the support in the community, so by default someone ends up going into an institution.

There are other factors. Ian Birrell made the very important point that there are perverse incentives. There are conflicts of interest. The clinician who is employed by the private provider of beds in an ATU has to make the decision on whether to end a sectioning. They are employed by the person who is making money out of keeping the bed occupied. That cannot be right.

The final point is that there is a lack of legal rights. Again, I strongly agree with Ian Birrell on this. We came out with a Green Paper in 2015, "No voice unheard, no right ignored," which made the case for looking at reforms to the Mental Health Act. We now have the chance of some reforms that will make a difference.

I would give people the legal right to a personal budget so that you really transfer power from bureaucracies or institutions to families of individuals to determine what care should be like for their family member. Care should be based around the needs of the individual, not based on the needs of an institution.

Q86 **Chair:** Thank you. We have had a bit of debate this morning about the Trieste model and what has happened in Italy. Do you think there are things we can learn from that?

Sir Norman Lamb: I was absolutely thrilled to hear of the Committee's interest in Trieste. Funnily enough, I visited Trieste in February last year, just before lockdown. I was totally inspired by what I heard. My main focus was on mental health, but they have deinstitutionalised the care of people with mental ill health, people with learning disability and autistic people. We have a massive amount to learn. They have demonstrated that the world does not cave in if you give people the chance of a better life in the community.

Your previous panel is absolutely right that, if we close down institutions, we have to make absolutely sure that we invest in the community. That is why this whole story so reinforces your Committee's strong position on the need for reform of social care and for more resources for social care. That is an essential precondition for getting this right.

Q87 **Chair:** Thank you. My colleagues have more questions for you, Norman, but I want to bring in Baroness Hollins. What do you think about the Trieste model? You have just submitted an independent report to the Secretary of State on the issue of independent care, education and treatment reviews for autistic people. Perhaps you could share with us

some of the findings of that report.

Baroness Hollins: Thank you very much. Of course, I think what they are trying to do in Trieste, and succeeding in doing, is absolutely what we should be doing in the United Kingdom. The point about it is that there has to be an attitude of inclusion and admission when necessary, but for a short period of time.

I set up one of the very first community learning disability teams in the country, in Wandsworth. I had a fairly small catchment area. I developed it. I had no out-patient clinic, no beds and no admissions except to the district general hospital, where people were admitted for two or three days and where the community team worked with the admitting team when there was a suspicion of mental illness that needed treatment, so that we could create a treatment plan. That was how we worked until we became overmanaged with the introduction of general management in the NHS. We were suddenly required to report our out-patient numbers. We were expected to fill our in-patient beds. The idea of working with families in the community just ceased to be the priority.

There was a failure, if you like, of clinical leadership. I always say that one of the things that psychiatrists did wrong at that time was failing to step up and be prepared to take roles in management. That is Trieste. I think it is absolutely right, but it will fail in this country if we do not absolutely commit to developing a different attitude and relationship between what currently I call people-land and service-land, where service-land does not really respect, it seems to me, the human rights and the basic humanity of the people we are talking about.

Let me move on to my panel. I have submitted a report. It has interim conclusions at the end of the first year of introducing and overseeing the use of independently chaired care, education and treatment reviews for people who are in long-term segregation—people who are secluded. It is very difficult to find out who those people are because at the moment there is no statutory requirement to notify long-term segregation. There are disputes about what counts as LTS. However, we found 77 people at the beginning of the year who met the definition of long-term seclusion. All of those people have had their care reviewed at least once by an independent panel.

What is important about the independent panel is that the regular CETRs are often chaired by commissioners. Our independent chairs are clinicians, mainly psychiatrists, but not only psychiatrists. Of those 77, we did a kind of qualitative, thematic review of the first 26 people. We looked at them, and the interim report is largely based on those findings and what has actually happened to those people, as best as we can tell, during that first year.

The findings were shocking. More than 50% of the 26 are autistic people. Many also have learning disabilities. Very few of them had any formulation; in other words, they had not had a multidisciplinary

assessment. They did not have a treatment plan based on a multidisciplinary assessment. Because most of them were there because of autism or a learning disability, there was no obvious point for them to be discharged. For most of them, if they were diagnosed as on the autistic spectrum, there still may not have been any expertise in autism in the unit. For many who were suspected to be autistic people, no autism assessment was planned. It was very rare to find any evidence of a sensory assessment, or an awareness of people's specific sensory or environmental needs. The majority of people had no life history there with them, yet I always ask the chairs to ask about any history of trauma.

Q88 **Chair:** We are going to have lots more questions on this, but I need to move on. It very strongly supports what Ian Birrell was saying about people with a non-treatable condition being detained indefinitely because somehow the system was trying to find a way to treat it.

I want to bring in Professor Phil Fennell and ask about potential legal changes. For example, we know that there is going to be a new mental health Act. Could that be a vehicle for sorting out this kind of issue? Could you, for example, give people a right to a personal budget, as Norman Lamb just talked about?

Professor Fennell: That could be done, but it is more likely to be done by amendments to health and social care than by mental health legislation. The White Paper that the Government have issued on reforming the Mental Health Act is tinged with green because there are many consultation points in it. The headline point in relation to people with autism and people with learning disabilities is that the Government clearly say, "We do not consider autism and learning disability to be mental disorders warranting compulsory treatment under section 3 of the Mental Health Act."

That is a very clear statement, but it is then qualified. It will be possible to detain somebody with autism under section 2 of the Mental Health Act for up to 28 days if they are manifesting severe distress such that they pose a significant risk to themselves or to other people. It will still be possible to detain people under the Mental Health Act who have autism or have a learning disability.

Q89 **Chair:** We have been talking about the Trieste model. In Italy, if you are being sectioned, the order has to be reviewed on a weekly basis. That puts a lot of pressure on the system to try to find an alternative to in-patient treatment. Do you think something like that could be a positive way of addressing the issues we have heard about this morning?

Professor Fennell: I am not sure that it would. There are proposals in the White Paper that would require a person to have a treatment plan within seven days of admission, which is almost lightning speed in the world of mental health. That treatment plan would have to be finalised by the end of 14 days. The idea of allowing an admission for assessment is

to assess whether there is a comorbidity, as the psychiatrists would put it—another mental health condition the person is suffering from which is driving their distressed behaviour.

The proposed Mental Health Act would not jolt the system by—

Q90 **Chair:** I am sorry to interrupt, Professor Fennell. We are trying to look at what would jolt the system. What are the changes in the law that would be that jolt? I think what Sir Norman Lamb was saying was that the voluntary approach basically failed. I am wondering whether if you said, after someone has been assessed—plucking a number out of the air—after a period of three months has passed, there has to be a weekly sign-off for sectioning by someone independent of their doctor, you could avoid that conflict of interest. Would that be a way that you could avoid what clearly happens sometimes—we do not know how much—when people are parked in a secure in-patient unit for appalling periods of time?

Professor Fennell: That is a possibility. The proposals in the White Paper are that a person would be able to appeal against detention within the first three months, within the second three months and then within the next six months. That is if they are detained under section 3. If they are detained under section 2, they can appeal their detention within—seven days of that 28—

Q91 **Chair:** We are losing you a bit, Professor Fennell. I will bring you back because a lot of people have questions for you. There is something wrong with the line. I am not sure if it is my end or yours. Apologies for that.

I want to bring in Dr Theresa Joyce, if I may. You were a CQC inspector. Can you cast light on an issue that we have not been able to resolve this morning, which is the extent of the poor treatment of some people with autism, some of the 2,200 people that we know are being held in in-patient units? Clearly, some terrible things happen sometimes. Is it your view that that happens a lot, or is it a very small proportion of cases?

Dr Joyce: I went to quite a few places in my role as an adviser. I was also involved in the restraint, seclusion and long-term segregation review. I visited a large number of places. The concerns that we have are that this is quite widespread, actually. I support Sheila's view. I looked at a whole host of things when I was visiting various places. The lack of care planning and the lack of knowledge about how to do good care planning was quite stark.

You would have forms that were filled in that looked like they were doing something. Yes, it looked like there was a functional assessment or a sensory assessment, but when you examined it in some detail they were not of very good quality, and they did not help to design what care the person was going to get. People were largely being cared for by staff who were unqualified. They were given very poor guidance sometimes by clinical teams who, I think, sometimes did not really have a handle on

what they should have been doing. There is an issue in both parts of that. It was very stark.

The issues around assessment and treatment lead to a lower set of expectations. Once a person is behaving in a certain way, we expect it of them, and the treatment that you give—which is often restraint or medication and not very focused on positive behaviour support—continues. You end up with quite demoralised staff who have low expectations and poor skills. Then you end up with what Ian talks about, which is a sort of institutional approach of depersonalisation and social distance, and you stop seeing the person as human.

I think we have that in too many places. There are some things we can do about it, but there are real issues and real concerns, which are borne out by Sheila, by parents all over the country and by the Challenging Behaviour Foundation.

Chair: Thank you. Let me bring in Taiwo Owatemi, who wants to talk more about restrictive practices.

Q92 **Taiwo Owatemi:** I am particularly interested in the use of restrictive practices on individuals in clinical settings. It would be good if you were able to elaborate on why those practices still exist. Baroness Hollins, what can be done to better regulate and reduce the use of restrictive practices in those settings?

Baroness Hollins: The difficulty is that people should not really be in hospital if the reason for being there is primarily containment of behaviour that has developed as a response to something traumatic happening, or to exclusion from the community and lack of community support. It is really tricky. It is a bit like the ICETRs. I am supposed to try to improve the number of discharges, or to monitor them and see how we can improve the frequency of discharges and the effectiveness of them, yet all the people we are looking at are, in a sense, subject to restrictive practices.

It is really difficult to discharge them. Of course, the trouble is that, if people continue to be admitted, we have a continuing stream of people who will be admitted into long-term segregation. Long-term segregation should be a notifiable thing; at the moment it is not. That would be one thing. I do not think that anything voluntary is going to change this at all.

Q93 **Taiwo Owatemi:** Thank you. Dr Joyce, are you able to elaborate from your own experience how you think this can be better regulated to reduce the risk of restrictive practices?

Dr Joyce: You are right. There should be better reporting and more attention paid when something is reported. Reporting something and just noticing it without taking any action is not going to reduce it.

In a sense, it is an organisational issue as well. What you actually need to reduce the use of restrictive interventions is to have things happening

that make it not necessary for the person to behave in a way that requires them to be restricted. That is what is not happening. If we had good training in positive behaviour support, and environments that allowed people to have their needs met, that would be much better.

In terms of regulation, clearly the CQC is doing more on trying to come to grips with all of this. It is always asked at inspections. The feedback from it in how we take action is what is currently lacking. We have a lot of reporting systems, a lot of policies and a lot of guidance, but what we need is a situation where we make sure that people can be discharged. I have a lot of concern about a discharge model that says, "They're not ready for discharge." The issue is that they will never be ready for discharge while they are in a unit that is toxic to their health.

We need to create community services that are robust and skilled, so that they bring people out rather than expecting the hospital to discharge, which it often does not have an incentive to do. We can have some models of bringing skilled staff in, like the previous closure programmes where a special development team went to services and brought people out, with local community teams. That had a big impact. We may need to think about something like that.

Q94 **Chair:** Can I bring in Norman Lamb on that point?

Sir Norman Lamb: When I was a Minister, I was asked by a family to visit a 15-year-old girl called Fauzia at St Andrew's, a large institution in Northampton. I went there and I heard how she was regularly restrained on a continuing basis, often put into seclusion—this is a 15-year-old girl—regularly breaching her human rights. I was absolutely shocked by what I saw. We got a review and got her out of there to a very good place in Northamptonshire called Alderwood.

I went back to visit her two years later. From the day she was discharged from St Andrew's to when I visited her two years later, she had not been restrained on a single occasion. This makes the point that Ian Birrell made: it is the setting, the institution, that is causing the problem in the first place. If you put an autistic person into a confined, alien environment, their behaviour is likely to respond, particularly if they are non-verbal. The change in that girl was remarkable. She was transformed as a result of coming out of that institution. That told me that the problem with the use of restrictive practices is their containment or warehousing in alien environments, when actually people could stand the chance of a much better life living in the community with support.

Taiwo Owatemi: Thank you.

Q95 **Rosie Cooper:** Norman, following your answer and the comments from Dr Joyce about training of staff, I think it is safe to say that you compound the difficulties if staff do not have the skills or resources to adequately care for and communicate with people with learning difficulties. You have often argued for a new role to be created to better

support autistic people and people with learning disabilities. Why is that new role necessary?

Sir Norman Lamb: It is a fascinating question, Rosie. First of all, with that young girl, Fauzia, I asked them at Alderwood when I visited her two years later what the secret was. They said to me that training staff in how autism affects a particular individual is critical, not just generic autism training but that every individual is different. That was a really important learning point for me. The idea of an intellectual disability physician is being developed by Ken Courtenay, who was on your first panel, together with my sister, Dr Kirsten Lamb, who was lead for learning disability in Hertfordshire, along with others. The whole principle is that we do not know enough about the complex interaction between a number of physical health conditions and learning disability. What we know is that very often they die, and the average length of life is much shorter than for other people. Life expectancy is diminished substantially.

The LeDeR programme, which looks at individual cases of deaths of people with learning disability, demonstrates that often the care is massively suboptimal. If you had a person who was skilled in the interaction between a learning disability and a range of physical conditions to guide the work of others in a hospital, and, critically, in the community setting—GPs but also social care staff—you would massively enhance the care and support of people with learning disability, and start to confront the shocking short life expectancy that we have completely failed to resolve over many years of trying. Incidentally, the Royal College of Psychiatrists and the Royal College of Physicians support this. Health Education England appears to be supportive. It needs resource. A recommendation from your Committee would obviously be very helpful in pushing forward the case for it.

Q96 **Rosie Cooper:** Thank you. Those comments are really quite shocking. It is incredible the difference it can make to anybody's life if you can communicate with them and listen to what they are trying to tell you, which in these circumstances is very difficult.

We have received particularly strong evidence from Mencap that we need to keep people with learning difficulties out of a hospital setting, yet there is also a view that in particular circumstances it may be preferable to have people in a hospital setting rather than in a prison setting. A new 40-bed low-security hospital is being built for autistic people and people with learning difficulties by Mersey Care NHS Foundation Trust in the north-west. Do you think building new facilities such as that is appropriate? Will they work?

Sir Norman Lamb: It is important to say first of all that I have not looked at the full case for and against. What I would say is that the case for it should be tested against the principles in the "Transforming Care" document. The principles in that document were first of all to support people in the community. That should be the aim wherever possible. When it is necessary to impose some restrictions on an individual, it

should be in small settings close to home. That is a really important principle.

I suppose my worry about the proposal for a 40-bed low-security unit is whether it takes people some distance away from home. If it does, that is a real worry for me. Does it give people the chance of a good life? Ultimately, these are people who may well have offended because of their learning disability or being autistic, and we should not punish them twice. We should be doing everything we can to give them the chance of a good life, and to reduce the chances of behaviour that challenges. We know that being contained in an institution, as I said earlier in relation to Fauzia, often triggers the sort of behaviour that then criminalises people, sometimes within an institution, making things even worse for them.

Q97 **Rosie Cooper:** We need to look at it in more detail because these are people who may have been charged with fairly serious offences, and it would be much better for them to be treated than to be in a prison setting. Thank you for that.

I would like to ask Baroness Hollins and Dr Joyce about the idea of people being close to home. We have heard that people with learning difficulties and autism are often kept in in-patient settings that are many miles from home and family. What do you think we can do, other than getting them out of those institutions of course, to ensure that they are placed closer to home?

Baroness Hollins: Yes, of course they should be supported close to home, and there should be specialist resources. One of the difficulties, when we think about the current legislation that requires that public services make reasonable adjustments to enable people with protected characteristics to access those services, is that it is increasingly understood in physical health services but still not properly understood in mental health services. If you have a learning disability or autism and you are sexually abused as a child, or a young person or an adult, the chances of you getting specialist trauma therapy for your abuse are minimal. Why? You should get the same access to specialist services as any other member of society, and this is a group that is more vulnerable to those kinds of abuses. It has to be done locally. It has to be by adopting an inclusive approach locally so that people can benefit from the sorts of services that are available to others. That is my response. I do not know whether it answers what you asked.

Q98 **Rosie Cooper:** We all agree that it should be close to home. I am an MP in Lancashire where my constituents could end up right across the county in Burnley and all sorts of places, and it is simply ridiculous. What can we do to ensure, almost to enforce, that they are close to home wherever possible, because they lose contact with their families and that kind of thing?

Baroness Hollins: Yes, family connections are so important, but that requires local commissioners. I would regulate commissioning. I would

require commissioners to be trained. I would hold commissioners to account for commissioning the right services in their catchment for people with learning disabilities and autistic people. Simple.

Q99 **Rosie Cooper:** Thank you. Dr Joyce, do you want to comment?

Dr Joyce: I agree. Obviously, they should be closer to home. We should be making sure that we are developing good-quality community services so that people do not have to go out and that they then can come back. We are in a situation where we have a here and now of people who are placed a long way from home, and still at risk of going. We could usefully be thinking about individuals who are at the end of a long system that has said, "We want to bring people back home, we want to do this, and we're going to do it." It comes from the centre, and when it gets to where the person is, it falls apart.

We need to identify some of those people and start working with them so that we have a person-centred and personally designed individual plan for them to come out. That is possible because we know how to do it. In a sense, we are failing them if we do not bring together the skills and resources we know we have to start doing that. It may be with named or identified individuals initially, but we should start.

Q100 **Laura Trott:** Dr Joyce, we have heard today about the need for in-patient settings in some circumstances due to clinical need or patient or family choice. However, equally, we have heard about some horrific situations that have occurred in those settings. What is failing in regulation, in your view, that this is still happening on a continuing basis?

Dr Joyce: That is a really good question. In terms of regulation, when the CQC goes into a service, it should actually look at things that need to be looked at to see if care is good. We cannot make the CQC totally responsible for the quality of care in a service, because there has to be responsibility from individual clinicians and from the trust or the hospital in which people are living. There must be accountability within the service as well.

For the CQC, there is a need, and it is starting to do it, to develop more robust measures for looking at the quality of what is going on in services and looking at issues around restraint and restrictive practices. If it is able to become tougher with those services and those organisations, we are likely to see more change. There is an issue about incentives. There has to be an incentive for people to do things differently. Currently, the incentives are not necessarily strong enough. Regulation is one. There may be financial ones that we could use as well. Getting tougher is not a bad thing.

Q101 **Laura Trott:** In the previous session, we heard that commissioners are continuing to buy places and services that the CQC has rated inadequate. We have also heard that the CQC cannot close inadequate hospitals if there is nowhere for people to go. Has that been your experience?

Dr Joyce: Yes. I am no longer with the CQC, but it was when I was there. It was very difficult. The CQC does close places, but that has a consequence for the people who are there. It is something you have to think about very carefully. If you close somewhere very quickly, what happens to the people who are currently in that service, and do they end up somewhere worse? We need to be able to track people if that happens. The CQC approach, rightly, is to try to improve practice. When it comes to a point where it cannot, clearly action has to be taken. I am not sure that answered your question.

Q102 **Laura Trott:** It did. Thank you. That was very helpful. I want to turn to Sir Norman briefly on the same question. Has the original institutional setting where Fauzia was now closed?

Sir Norman Lamb: No, it is still open, and still very substantial, and an important point—

Q103 **Laura Trott:** Sorry to interrupt. Is that not extraordinary? Given that you were a Government Minister who took up a case of, frankly, what sounds like abuse of an in-patient there, the fact that the setting is open and still has patients in it is, to my mind, an extraordinary outcome.

Sir Norman Lamb: It is the wrong model of care. I agree with you. What frustrated me through my time as Minister was that I would often speak to the CQC and say, "We can see that a lot of private sector companies are making substantial investments in new facilities providing the wrong model of care. Do you not have the powers to stop them being registered in the first place?" It appeared, they claimed, that the fear of legal challenge if they were to refuse a registration stopped them intervening in that way.

I agree with Theresa Joyce that it should not just be down to the CQC, but the CQC should be taking a tough stance. If we know that institutions provide the wrong model of care, we should give the CQC the power to prevent new ones from being opened and to stop this ridiculous flow of investment into that wrong model.

Q104 **Laura Trott:** You think that the fear of legal challenge is the key thing that is stopping the CQC shutting down institutions that may be inappropriate.

Sir Norman Lamb: That is certainly what they told me at the time, when I was trying to encourage them to act to stop new facilities opening. Throughout this period, when the central policy of Government and of the Local Government Association is to transform care, you have this extraordinary, continued investment in private facilities maintaining and perpetuating the wrong model of care.

Laura Trott: Thank you. That is very helpful.

Q105 **Barbara Keeley:** Sir Norman, you talked about the case of Fauzia and Alderwood. It was very good that she could be moved, but, as we have

just heard, that institution is still there and people are potentially in the same situation.

We know that lack of community resources and funding them is a major issue. Potentially, this has derailed, in part, what you were trying to do in transforming care. Did you look at a system of dowries that would have transferred a pot of money from the funding of the NHS for in-patient unit placements to a local authority, as we had some decades ago when long-term psychiatric institutions were wound down? I was, that time ago, a councillor and vice-chair of social services. We used to have a substantial sum. Resettling somebody like Fauzia and somebody like Bethany, whom we heard about earlier, is probably quite expensive. You need housing. You need to train the staff in the way that you talked about them having been trained for Fauzia. Did you look at that? Is it something we should look at?

Sir Norman Lamb: It was ultimately tried for a period of time after I left the Department as part of the transforming care programme. The "Transforming Care" document in 2012 said we should either pool budgets or shift resources from the NHS to social care. That has not happened. When I think about someone in Fauzia's position, I would look at approaches that would stop her going into that hospital in the first place.

In my own county of Norfolk, there is a brilliant service called Starfish+, led by a brilliant psychologist, Dr Mel Bruce. Their whole approach with young people, children and teenagers is to stop them going into an institution in the first place. Through crisis support to families through the most difficult periods, they manage to avoid admissions that in other parts of the country routinely happen. They demonstrate that it is possible to keep young people out of institutions. You have to get it right in those early years.

Q106 **Barbara Keeley:** Indeed. But if they do not exist, you have to create them. Creating something like that is really difficult. What we are trying to get to is how we can, as a Committee, point out what needs to be done to create that. The transforming care partnerships clearly were not very good. The old dowry system used to work. Perhaps it is something to be looked at.

Sir Norman Lamb: It is a good measure, but ultimately your Committee has made the case for the need for extra resources for social care, which would also help to resolve the problem.

Q107 **Barbara Keeley:** Indeed, it would.

Theresa, we heard about the development of the Mersey Care hospital that my colleague, Rosie Cooper, just talked about. There is concern that the type of institutions that we are talking about might shape-shift, if you want to put it that way, and start registering as care homes that are functionally identical to the in-patient units and even operated by the same company. If we get institutions renamed, or services reconstituted,

as supported living settings, as it currently stands, that would not help the people there. How can we get a move away from the type of unit that is not working and is abusive, to the type of small-scale provision that Sir Norman Lamb has just talked about?

Dr Joyce: If a hospital tries to re-register as a care home, and it is on a hospital site and is not part of a community, the registration probably would not be allowed to happen. I appeared at a couple of tribunals where hospitals had tried to do it, and we won the appeals. People take legal action sometimes, and we have to defend it. That did not happen.

If they are trying to change to supported living, it becomes more difficult because the CQC only regulates the personal care aspect. Then, you are in a much more difficult situation. I know it has a new registration policy out now that will try to address that. Legally, it is a much more difficult path to follow, but it can refuse and hopefully would continue to refuse to register a change of use from a hospital to a care home with nothing else much changing.

Barbara Keeley: Thank you.

Q108 **Dean Russell:** I would like to ask Professor Fennell the next question. As well as being on this Committee, I am also on the Joint Committee on Human Rights, where the issue of care homes and in-patient care for autistic people and people with learning disabilities has come up repeatedly. The concern I have is that it sounds like, at a legal level, there is lots of legislation and there are lots of Government directives to support people, but what I am hearing on the ground is that there are some awful practices going on. I want to get your sense of what needs to change. Is it a better whistleblower programme? Is it a national register of how long people are kept in in-patient care? What is the solution? It feels to me that, at the top, the directors are coming down to treat people in the right way, especially from a human rights perspective, but, on the ground, families are sharing awful stories. It is really concerning that it feels like it is a "See no evil, hear no evil" scenario at the moment.

Professor Fennell: Yes, it is. We have been looking at the issue of providing crisis intervention since the 1970s, and we have failed to do anything properly with it. We have a horrendously complicated system of mental health and mental capacity law. You can be detained under the Mental Health Act. You can be detained under the Mental Capacity Act. Indeed, more people are detained under the Mental Capacity Act than are detained under the Mental Health Act. My concern is that, if we say that we are going to restrict detention under the Mental Health Act, the result will be that people will be detained, if it is thought that they need to be detained, under the Mental Capacity Act. That contains far fewer safeguards and far fewer protections against being treated without consent and against being detained. That is a worry.

The one thing that could be done is properly bringing into force the Mental Health Units (Use of Force) Act 2018, the so-called Seni's law,

after Seni Lewis died after being restrained by 11 police officers in Bethlem hospital. That Act was passed in 2018 and needs to be properly brought into force. We would then have a handle on what is going on restraint-wise in these institutions. Of course, it is ridiculous that we have people being transferred 200 miles from their relatives and kept in those places, and then unable to convince a tribunal that they no longer need in-patient care because they have become so distressed in that setting. There are things that could be done.

The White Paper tries to tackle the issue of commissioning. One of the things that Julie Newcombe said was that we need to enforce the existing laws. One of the laws she mentioned was the Mental Health Units (Use of Force) Act. The other law she mentioned was the requirement that commissioners have adequate community resources for people with autism and learning disabilities. The Government's White Paper proposes to put that as a duty into the Mental Health Act reforms. It also proposes to introduce a duty whereby local authorities will keep an at-risk register of people who might need services. We also need the Mental Health Act statistics to be accurate. They are not at the moment. Many of them are based on estimates.

Q109 **Dean Russell:** Very briefly, in a yes or no, because I want to give time for my colleagues to come in, would you say the direction of travel with the Mental Health Act is in the right direction? Of course, with anything like this, we need to do more.

Professor Fennell: There is a definite recognition that there needs to be some special provision outside the Mental Health Act for people with autism and learning disabilities. The White Paper tries to ensure that people who have autism or learning disabilities and an accompanying mental disorder are not denied treatment for that because of the fact that they also have autism or learning disabilities.

Dean Russell: Thank you.

Q110 **Dr Evans:** We have heard a couple of times about perverse incentives. In some of the far east one of the ways in which you judge your doctor is not by payment at the time you are unwell; they pay you while you are well, and you do not get paid as a doctor when you are unwell. I wonder if there is an incentive. This is a question to Dr Joyce and Norman Lamb. Would it be worth, on that basis, turning around the incentivisation, and institutions were paid for keeping people out of their institution? By definition, they would be paying people to remain in the community and only coming in when their services would be needed. It would certainly create a very different atmosphere. What are your thoughts on that radical position?

Sir Norman Lamb: I absolutely agree with what you are putting forward. You point towards the idea of incentivising good outcomes for people. A good outcome for someone is that they have the chance of a

good, happy and fulfilled life in the community. People who enable that to happen, it seems to me, should be rewarded.

There is a professor who works in my institution, at the Maudsley, Professor Paramala Santosh, who has done brilliant work using digital means, working with families getting them to complete questionnaires on a monthly basis so that you can start to monitor someone's condition. If you enter that into digital means and you then use artificial intelligence to identify when there might be a deterioration of condition, you can intervene early to stop the necessity of an in-patient admission. Using digital support in a clever smart way, working with families, can also be part of the approach that you advocate.

Q111 **Dr Evans:** Dr Joyce, is it practical? We have heard that it could potentially work.

Dr Joyce: It is an interesting idea. I would have to give some thought as to how you would do it in practice. If we started measuring and incentivising opening and developing good community services instead of measuring bed closures, it might start shifting the balance, because people pay attention to the thing they are asked to report on. I will close a bed, but I do not have to demonstrate what I have done to replace it in an effective way.

Q112 **Chair:** Before we wrap up—and we have to wrap up, I am afraid, pretty promptly—can I ask each of you to give me a 15-second answer? We know what the problem is: too many people with autism and learning disabilities detained quasi-indefinitely in in-patient units are sometimes treated appallingly. What is the single change that needs to happen that would solve the problem? You first, Sir Norman.

Sir Norman Lamb: I would focus on getting it right for children and sorting out the awful problems we have with transition. The biggest number of people get admitted between the ages of 18 and 30, just after everything has been taken away from them in terms of support at the age of 18. That has to be resolved, together with proper supported social care.

Q113 **Chair:** Thank you. Sheila?

Baroness Hollins: I would stop the focus on crisis intervention, and develop continuing relational-based support and care planning, noting that a number of people were admitted with unrecognised, complicated grief after a parent died. I would charge the community provider, the community services, for any admission, and I would base that on the successful way it was developed by Professor Robert Sovner in Massachusetts 20 years ago.

Q114 **Chair:** Thank you. Fascinating. Maybe you could write to us with some details on that if you felt able to.

Baroness Hollins: I will.

Q115 **Chair:** Phil?

Professor Fennell: I would try to learn from the experience of Ely Hospital, which was closed down in the late 1960s/early 1970s and everybody was resettled. I would go back and learn from that.

Q116 **Chair:** Thank you. Theresa?

Dr Joyce: I would use a model that we know works, which is to bring together some skilled clinicians who know how to do this, and bring them to the places where we know people are and use their skills to help people come out, and develop competence in local services so that we get people out who are currently living in really poor circumstances.

Chair: Thank you very much indeed. That concludes our second panel. A very big thank you, Professor Fennell, Dr Joyce, Baroness Hollins and Sir Norman Lamb. Your testimony was extremely powerful, very helpful, very practical, and will help us enormously in the report we are putting together. As you can imagine, Norman, having been a Minister, we are looking for practical things that we can change, not just another chance to restate the problem. We have had a very good discussion on that.

I add my personal thanks to Sir Norman Lamb for his commitment to these issues when we were both Ministers together, and for the extent to which he helped to develop my own understanding of the issues. You do not often get a chance to put these things on the record, but I am proud and happy to do so today.

Thank you all for your time. It is enormously appreciated. Thank you to our witnesses on the first panel as well. That concludes this morning's session.