HOUSE OF COMMONS

Health and Social Care Committee

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

Tuesday 9 February 2021

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Watch the meeting

Members present: Jeremy Hunt (Chair); Paul Bristow; Rosie Cooper; Dr James Davies; Dr Luke Evans; Barbara Keeley; Dean Russell; Laura Trott.

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Witnesses

I: Alexis Quinn, Autism Activist, Author, Restraint Reduction Network Manager.

II: Dan Scorer, Head of Policy, Public Affairs, Information and Advice, Mencap; Vivien Cooper, Founder, Challenging Behaviour Foundation; Ivan Olbrechts, Representative Body Member, Learning Disability England; and Julie Newcombe, Co-Founder, Rightful Lives.

Examination of Witness

Witness: Alexis Quinn.

Chair: Good morning, and welcome to the opening Health and Social Care Select Committee evidence session on the care received by autistic people and those with learning disabilities. This is a short inquiry and we are specifically focusing on the care received by around 2,000 people in secure in-patient settings.

This is a group of people who have suffered particularly badly during the pandemic. We will look at that, but also at longer-term issues with their care, including the forcible use of restraint, seclusion and segregation. We are particularly going to look at progress towards the Government's stated objective to reduce the numbers of people in such care by half from 2015 levels by the last year of this Parliament.

Our first guest today is Alexis Quinn. We are delighted to see you Alexis. I know that you have given evidence to House of Commons Committees before. Alexis was diagnosed with autism when she was 30. She had some terrible experiences with her care and has since become a formidable and very well-known campaigner for better care for autistic people. Thank you very much for joining us, Alexis. Our Committee member, Dean Russell, is going to ask you a few questions.

Q1 **Dean Russell:** Hi again, Alexis. We spoke recently when I was on the Joint Committee on Human Rights. Thank you so much for your time.

My first question is, nearly five years on, how do you reflect on your experience of being detained in an assessment and treatment unit?

Alexis Quinn: First of all, it has been much less than five years since I have been detained for autism—much less. Detention is always a threat if you are autistic. Any kind of autistic reaction to stressful life events like divorce, bereavement, going through puberty or changing year group at school can, and too often does, result in sectioning, because there is literally absolutely no community-based understanding, support or provision whatsoever. Sectioning is a constant threat that many of us have to live with, including myself.

When I reflect on my time in the system, I reflect on being othered and not being treated quite as a human, and being told constantly that I need to get better, though from what I do not know. My goals for three and a half years were not my own. They were constantly out of reach because I could not change by embodied disposition. I was rewarded with star charts and fresh air if I managed to look normal, and was confined indoors if my autistic-ness and reaction to the environment could not be adequately masked that day. I was put at odds with myself and grew to hate the autistic part of myself, which I had never hated before. I often say that I was helped to hate myself by professionals.

I reflect on being transported in cages and handcuffs. My legs were tied together in safe straps, though they did not feel very safe, with one strap above the knee and one below. I was carried like a battery ram. I reflect on closed doors, being hundreds of miles away from home and worried when the next sensory overload would come, triggered by a chaotic and sensory-charged environment that I had no choice to be in. Doors were closed and there was no way of modulating my sensory system. I run a lot to enable myself to do things during the day. Obviously, when you are in hospital you cannot do that.

I was constantly worried because I was just waiting for the next overload to come. It was always met with six to 10 men pinning me to the floor, pulling my pants down, injecting me with sedatives and then secluding me, where each minute just felt like an hour. I reflect on the time I spent in long-term segregation with just a mattress and pillow on the floor. I reflect on the lights shone every hour through a window this big in each door of the room that I slept in. You would not believe that for a good few years I missed being woken up every hour by a torch. You get so institutionalised.

I reflect on how the system just does not care about autistic people and how it silences you and makes you afraid. That fear stays with you for a long time, even now.

Q2 **Dean Russell:** Thank you for sharing that experience. I have a few more questions, if I may, but thank you so much for sharing that. Reflecting on that, do you think it was right that you were there? How did staff treat you while you were there? I know you mentioned it just now, but what upset you about your treatment, if you don’t mind saying?

Alexis Quinn: I absolutely needed help. Like many autistics, I am sensitive to change and to crisis. I was not managing. The thing for me is that the help I got was not appropriate. I needed speech and language therapy, OT and some psychology, which may have cost less than £5,000. Instead, millions were spent on turning me into a wounded storyteller.

How did staff treat me? Most staff do their best. They are part of a system that just doesn’t work and is not fit for purpose, if I might say so. There needs to be a huge culture and paradigm shift. For me, the main problem with the system is that it is sink or swim. If you cannot manage in the community, then to hospital you have to go. It is that polarised. Hospital is the most inappropriate place for autistic people. You get restrained. Restraint should be a last resort, when there is an immediate threat to self or others, but it isn’t. It is used to ensure compliance and for coercion. To be honest, it is used to manage a larger ward environment that is usually understaffed. That is not restraint. It is manhandling and abuse, and we need to start calling it that.

The most upsetting thing for me long term is the routine criminalising of autistic people. If someone is kept in a locked environment that we know they cannot manage and that their autistic disposition is sensitive to, why are we being prosecuted when we are in a meltdown? Why are we being charged with assault and criminal damage? Yes, people are kicking at doors because you have locked us in a room for days, weeks, months or years and we want to get out. Obviously, we are going to fight to get free.

It is life limiting. It is life limiting for me. I am representative of many people it has happened to, and I am suffering the injustice of being criminalised right now. I do not think we deserve that. That is probably the most upsetting thing. We have been failed. First of all, we have been labelled. You have imposed on us this label and what that means to us. Now we are paying the price, after we have left an environment that was pretty awful.

Q3 **Dean Russell:** Thank you for sharing those experiences again. You have had a lot of experience now. You have spoken to a lot of people and you have obviously given evidence at sessions like this. Do you think that anything has improved in ATUs since you were detained?

Alexis Quinn: No. I do not think anything has improved at all. I think it cannot improve. As I say, it is a constant threat. The model of care is wrong. It is reactive. It is over-medicalised. Let's remember that we are not sick. Why are we in hospital?

I am not saying that people do not need help and support, because we do. Of course, we do, but we need care in single occupancy or a couple of people in a crisis house, or in a setting designed to meet our unique sensitivities. We need care for as long as we need it. Our families and friends need to be supported. Often families are sidelined, especially my own. It is not just me left traumatised; it is them, too.

The model of care is brutal. It is aggressive and not supportive. If you were thinking about what an autistic person needs, you might say routine, familiarity and capability-based support. What do we get? Routineless, chaotic, sensory-charged warehousing, often miles away from home. I was 400 miles away from home sometimes. We need predictability, and none of that is there. Instead, we get restrained, secluded and long-term segregated. Obviously, that remains the same.

Q4 **Dean Russell:** We hear stories and take testimonies from witnesses. You have probably heard more than most. How does it make you feel when you hear that other people with learning disabilities are being treated badly in in-patient units?

Alexis Quinn: It makes me feel determined. It is not over for me. It is not over for us—for all autistic people who are out of hospital now or those who are in hospital. I often say that we are one meltdown away from an admission.

I do not want to make it sound like it is about being treated badly or about the staff. This is not all about the staff, hospitals and warehousing. It is bigger than that. It is about medicalising something that does not need to be medicalised. It is about a system that has so little flexibility in the way that it helps and cares for people that, quite predictably, we are going to react. It makes me determined. We need to put something in place for the everyday life events that we know autistic people and learning-disabled people are sensitive to.

I had a baby last year and nothing had changed. The only thing that had changed was my capacity and wherewithal to realise that I needed a decent human rights lawyer to get me the reasonable adjustments I am legally entitled to. Not everyone can do that when an event is happening. The fact is that support is not available. The end. Full stop. It is as simple as that.

Q5 **Dean Russell:** Thank you. We have incredible witnesses on the panel today. No doubt this Select Committee will be widely watched. What do you think needs to change?

Alexis Quinn: We need to stop the deficit-based narrative. It directly impacts on how we are treated. If we are seen as other, we will be treated as other. I think we need to take a capability approach, asking people, "Where are you at now? Where do you need to be?" Government need to prioritise those services. They have to be community based. It is not about getting people out of hospital or stopping people going in. The services need to be there. If they are there, the problems will resolve themselves.

It is a rights-based approach to help people in crisis. I know that term is bandied around, but we certainly will need support, especially mental health and crisis support. As I say, we need community-based crisis housing, trauma-informed care and trauma therapy. All of those things are paradigm shifts. It is about organisational change.

Of course, we need a workforce that can do all of that. We need small providers, and we need those providers to put people first, and not just say that they do. The privatisation of mental health care needs to stop.

Many people have been targeted by big providers and gagged. They rightly fear repercussions from speaking out. I suppose I am lucky, in that at the moment I can talk to you and not fear those reprisals. This work of giving evidence and suchlike is re-traumatising for people. Retelling our stories is important for the purpose of improving the system and the lives of others. I am happy to do it and I will tell my story over and over, but we have told them many times before and nothing has changed. I hope that after today something will change. If you guys have any power to stop this endless evidence-giving and for some real change to happen, please do that.

Dean Russell: Thank you, Alexis. It has been a pleasure to speak to you. Thank you for such powerful, personal testimony.

Chair: Alexis, I know that I speak for all of us in saluting your incredible courage in coming forward and speaking out like that. We do not really know the answer to your question. We do not have any power, but we may have some influence, although we do not know how much. All I will say is that this is the very first evidence session of the inquiry, and what you have said has powerfully shaped the way that we approach these issues. Thank you for doing that.

We are going to hear evidence from a number of organisations that are working with autistic people and people with learning disabilities. If you want to make any more contributions on the basis of what you hear from other people, just wave at your camera. Hopefully, one of us will spot you, and I will try to bring you in. For now, thank you very much for that very powerful and shocking evidence.

Examination of Witnesses

Witnesses: Dan Scorer, Vivien Cooper, Ivan Olbrechts and Julie Newcombe.

Q6 **Chair:** We are now going to hear from some organisations that are all very closely involved in improving the way that individuals with learning disabilities and autism are looked after. On this group of panellists, we have Julie Newcombe, whose 23-year-old son, Jamie, spent 19 months in in-patient settings, where he was repeatedly assaulted by staff. She founded an organisation called Rightful Lives. Vivien Cooper's son, Daniel, has a rare genetic condition and she struggled to get advice on how to support him, so she set up the Challenging Behaviour Foundation.

Dan Scorer is head of policy and public affairs at Mencap, and has campaigned for a long time for the rights of people with learning disabilities locked in secure settings. Ivan Olbrechts is from Learning Disability England, as well as being a part-time family carer for a nephew with autism. Thank you all for joining us.

This is not the main focus of the inquiry today, but I want to start by briefly reflecting on the challenges that people with learning disabilities and autistic people have had during the pandemic. Dan Scorer from Mencap, do you think that people with learning disabilities and autistic people and their carers have received enough support during the pandemic?

Dan Scorer: No, I do not. It is very clear from everything that people and their families have said. We can look at that across social care and health. From a survey of over 1,000 family carers that we did during the first lockdown, around 70% had experienced a reduction or cut to the social care support they and their loved one were getting. When we followed that up in November, 80% still had not had services reinstated. Many people have been shielding and have been extremely worried about staff coming into the family home, so caring responsibilities have gone up considerably for many family members, who have taken on a huge weight of responsibility. In addition, many services in the community, like day centres, have closed. That has seen daily routines completely disrupted or changed for many people with a learning disability, with family carers taking on huge additional responsibility.

On health, there have been major issues with Government guidance. For example, when someone with a learning disability is going to hospital or is in an ambulance going to hospital, it is absolutely vital that family members and carers are able to go with them. Those key reasonable adjustments have not always been built into guidance. In March last year, the NICE acute care guidance was published, which applied the clinical frailty scale to disabled people of working age and, in some cases, could have denied them treatment in hospital. Many of us campaigned to get that changed, and it was. That was combined with lots of concerns around things like the application of do not resuscitate orders. There have been major concerns about whether people with a learning disability can get access to treatment and, when they can, as Alexis said, whether the right reasonable adjustments are made for them. Throughout the pandemic, there have been huge challenges for people and their families across both health and social care.

Q7 **Chair:** Let me bring in Ivan Olbrechts on that issue. During our inquiry into the country's response to coronavirus, we heard concerns that people with learning disabilities have been towards the back of the queue for things like testing, arranging family visits and vaccinations, and have not felt that they have been given the priority they deserve. Is that a fair comment?

Ivan Olbrechts: I think so. It varies hugely. I am very pleased that my nephew has been vaccinated, but, oddly, his mum, who is his main carer, was not at the time. That may be something to think about. It is a very mixed picture; some people with learning disabilities are the sixth priority.

Q8 **Chair:** Julie Newcombe, how has Jamie been coping during the pandemic?

Julie Newcombe: He was living in a very nice residential home about an hour or an hour and a half away from us, depending on the traffic. Last March, when things started to look a bit dire, we thought that the best move would be to bring him home to live with us. It was a tricky decision, but fortunately one of the advantages of working from home is that my husband is around to help. Also, his brother and his brother's fiancée were around.

It was an easy decision to have him at home, but it has been hard work. His routine has been completely disrupted. Everything that he likes to do he cannot do. We have had to be quite creative about finding alternatives. We are lucky; we have a house with a garden. We bought a trampoline and paddling pool over the summer—perhaps not now—which meant that we could provide alternatives for him, but it is becoming more and more difficult over the winter months to keep him occupied. When you consider that he has post-traumatic stress disorder as a result of his experiences in hospital, that means it is really hard work for us as a family because there is no respite from him. The nights are dreadful, and the days are hard. At the end of the day, we still felt that being at home was better than him being in his home without us being able to visit.

Q9 **Chair:** Vivien, can I ask how Daniel has been during the pandemic, and what are your general observations?

Vivien Cooper: They are similar to all the issues that people have already talked about. Daniel lives in supported living, with an individual service and his own staff team. Because they are just focused on Daniel, they have been very Daniel-centred in thinking about how to manage the situation.

We were able to see him regularly until recently. It is like everyone who has spoken previously. He is not able to understand the pandemic. He is not able to understand why he cannot do his normal things. He is not able to understand why he cannot go out. Initially, it was very difficult because he is very active and needed to be out. He goes out at least three times a day. When the first lockdown guidance came out, and you were only allowed to go out once a day for an hour, we had to fight quite hard—we collectively, a whole range of people—to get some special guidance around that. For him, being indoors all day, every day, and only going out once a day would have meant a huge escalation in his behaviours, which could have led to a whole load of other things, as Alexis has already described.

On your question about being at the back of the queue, yes, it seems that people with learning disabilities and autistic people were an afterthought when guidance was being developed, rather than being at the forefront of thinking about what special measures needed to be in place to ensure that they could be supported appropriately.

Q10 **Barbara Keeley:** I will put this question to Dan first, but others might have an opinion on it, too. There was quite a shocking report from Public Health England in November 2020 on the death rate for people with learning disabilities during the pandemic. It was 4.1 times higher than the general population, and in some age groups—the young, 18 to 34 age group—it was very high, at 30 times. Dan, what is your understanding of the reasons behind that figure?

Dan Scorer: When the figure was adjusted for age it was over six times the death rate, compared with the general population. We have already touched on many of the reasons behind that. We have to remember that, before the pandemic, people with a learning disability were dying more than 20 years earlier than the general population. The important research that the learning disabilities mortality review has done over recent years showed us that, even before the pandemic started, people with learning disabilities faced systemic exclusion from access to health services, with over 1,000 dying avoidably every year when, if they had had access to good-quality and timely healthcare, their lives could have been saved.

There have been many challenges. Large numbers of people have struggled to understand the ever-changing guidance on knowing how to stay safe and what to do. That has been incredibly difficult for people to understand.

In terms of access to health services, huge amounts of elective surgery have been cancelled. There has been a huge fall in the number of people attending emergency hospital services. We have had lots of inquiries from people struggling to access healthcare and not knowing where to turn or whether it is safe to go to hospital. There is major concern that lots of people who needed to access healthcare services did not feel able to or were not able to.

As well as that, now with the vaccination, which Ivan just touched on, while we have adults with Down syndrome in priority group four and some people with severe and profound learning disabilities in priority group six, it is deeply worrying that we do not have all people with a learning disability included in at least priority group six, along with unpaid family carers, when the death rate is so high. I am sure that the inquiry on the handling of the pandemic that will follow will look into precisely the reasons why the death rate among people with a learning disability is so high, and the changes that need to be made as a result, but, as I said, even before the pandemic there were huge issues of premature mortality and people not being able to access healthcare.

Q11 **Barbara Keeley:** Following up on what you said earlier, how much do you think issues like staff and supporters not being allowed to attend hospital with the person with a learning disability and the do not resuscitatef policy have played into this?

Dan Scorer: The problem with guidance blocking visits to hospital is a huge issue. If someone with a learning disability is admitted to hospital and they cannot communicate or they are non-verbal, they rely on family members and carers to advocate for them. That is absolutely essential to make sure that staff in the hospital can understand the person's needs and put in place the right kind of care and support for them. If that is not there, it is a massive problem. With the NICE guidance, it was of enormous concern that the clinical frailty scale was applied to disabled adults of working age, potentially denying them treatment solely because they need care and support services. It was reversed after an outcry, but that guidance was out there.

There were lots of concerns, which the Care Quality Commission is now looking into, around the inappropriate use of do not resuscitate orders without proper, lawful consultation with people, their families and their carers. There have been very serious concerns about access to healthcare, and potentially unlawful practice.

Julie Newcombe: It is really important to remember that the LeDeR figures do not include autistic people who do not have a learning disability. The situation is probably worse if you include those people. I have no idea what the figures are, but it is something that possibly needs to be considered. Autistic people, for similar reasons, have found the pandemic difficult.

A lot of autistic people cannot even talk on the telephone particularly easily. They find it really daunting. I am sure Alexis could explain more. It is important to remember that there is a group of people out there who have not been considered: autistic people who do not have a learning disability.

Barbara Keeley: That is a good point. Thank you.

Q12 **Chair:** I want to move on to more general questions. It is not that this is not a very important area, but we have covered it in quite a few of the other evidence sessions we have been hearing. I want to look at the more long-term issues of policy around the people who are held in in-patient units.

I want to start with Julie, if I may. You campaigned very powerfully after the treatment received by Jamie. Currently, we have about 2,000 people with learning disabilities and/or autism in 96 locked in-patient units across the country. On the continent, Italy took the radical step of banning all new admissions to public mental health hospitals and has moved all care to a community-based system. What is your view about whether we need those wards at all, given the experiences you had? Do you think we should look at following Italy and ban in-patient admissions, except perhaps in forensic cases?

Julie Newcombe: There would be a lot to be said for looking at that. The vast majority of those 2,000 people do not need to be there. If you have a handful of people who possibly may need some kind of restricted setting, you certainly need to make it a lot more pleasant for them than it is currently. The vast majority of those people can live in the community. There is plenty of evidence to show that they can.

If you look at the work done by the National Development Team for Inclusion's small supports project, where small, values-led providers put the person at the centre of everything and see them as people with potential, dreams and hopes and not as some kind of risk profile, you can see how very successful lives are lived. There is a wonderful book by a colleague of mine, Alicia Wood, called *Helping People Thrive*. In it there are real-life examples of some really troubled people—"troubled" is probably the wrong word—people with hefty reputations, as we like to say, who have spent years in those in-patient settings, and then come out, with the right support, to lead meaningful lives. There is a lot of evidence to show that it can be done.

If you were to suddenly say, "Let's ban all in-patient admissions," the only worry I would have about that is, what is the alternative? There is a dearth of the right kind of community care. The priority has to be to start looking at getting the right kind of community care in place. That will be done with the right values-led organisations leading it, and with true leadership from the top and at local level.

We need the funding to make it happen. I know that money is a bit of a moot word, but when you consider how many millions we spend on putting people into those hospitals, it really is just a case of some ring-fenced double funding up front—heaven knows where the Transforming Care millions went—and it needs to be spent on getting community placements and community services in place so that people have those opportunities.

The most important thing is to remember to ask people what they want and what they need. We must not assume that we know what an autistic person wants or what a learning-disabled person needs. We need to ask them and talk to them about what they want and need.

Q13 **Chair:** Maybe you could reflect on or tell us about some of the things that Jamie experienced, and whether they are linked to being in a large institution. Would they have been avoided if he had been in a much smaller community setting?

Julie Newcombe: Yes, definitely. Jamie spent 19 months in five different hospitals. None of them knew what to do with him, and none of them was suitable. They just kept transporting him from one to the other in a cage in the back of a van. That says something in itself. Those places themselves were saying, "Well, we don't know why he is here. We don't know what to do with him. Let's move him somewhere else."

If he had had the kind of support that he had when he came out of hospital—he had not changed; he was still the same person—I think we would have seen a very different scenario. He has now been out of hospital for over five years. In all that time, there have been no restraints. There has been no need for excessive amounts of PRN medication. He has been to college and done a college course. He has done voluntary work in the community. He gets out and about and leads a great life. He has not changed; it is just his environment and the way he is treated.

Q14 **Chair:** Thank you; that is very powerful. Ivan Olbrechts, should we follow what Italy has done?

Ivan Olbrechts: Yes, although I echo what Alexis said earlier and what Julie said. People may need trauma and mental health support as much as the next person, but it does not need to be in in-patient detention with little or no therapeutic benefit.

At the San Giovanni hospital, they went from a population of around 1,100 down to 50, due to mental health reforms. That was in the 1970s and seems to have a better track record than we have achieved through the Transforming Care programme. There is clearly something to be learned from their community-based approaches.

Q15 **Chair:** I was Secretary of State when we were trying to implement Transforming Care. The interesting difference is that there was the power of the law behind what they were doing in Italy. They changed the law to ban in-patient admissions. That forced change, whereas Transforming Care was a more voluntary or consensual process. Do you think that is why they made better progress in Italy?

Ivan Olbrechts: We have human rights laws here. Part of the problem is not the Act itself; it is how people are applying it, particularly around the requirement to have alternative provision and something to discharge people to. That absence is probably the primary reason that people are kept in. I second everything Julie said about what you need to do in order to create and stimulate that provision.

Q16 **Chair:** Thank you. Let me bring in Dan Scorer. What is your view?

Dan Scorer: We are very clear that in-patient settings are extremely damaging to people. If we look at the environment, as Alexis set out very powerfully, it is not suited to people with autism. There are bright lights, noise and staff constantly changing around, which is not the kind of environment that is remotely therapeutic for people; it is actively damaging and triggers behaviours that then reinforce justifications for detention.

We touched earlier on restricted practices and people being given anti-psychotic medication who do not have a mental health diagnosis. Alexis talked about the appalling use of physical restraint, including prone restraint, and people being kept in seclusion and segregation. All of those practices amount to a system that creates lasting physical and mental trauma and is not meeting people’s needs.

In relation to assessment and treatment units, we have to remember that they are places that people in crisis should be going to for a period of weeks or months, yet the average length of stay is over five years. They are hospitals. They are not homes, and they are not places where people should be staying for that length of time; they do not make people better who are not mentally ill but just have a learning disability and/or autism.

Q17 **Chair:** To be clear, Italy did that radical change where it banned in-patient admissions by law. Do you think that is the jolt that our system needs, with all the caveats that we have heard from Julie and Ivan about making sure that you have community provision? In some ways, the argument goes that with that jolt you force the system to provide the community care that it may not provide unless it has that big legal change.

Dan Scorer: The jolt is undoubtedly needed. Julie set it out very clearly earlier. We need alternatives in the community. You cannot just discharge people to nothing. Indeed, that is one of the reasons why the Transforming Care programme has not achieved any of its targets. It is focused on bed closures and not focused sufficiently on building the right support—the housing and the trained staff teams that we need in the community.

If we were looking at banning in-patient admissions, we would have to do all of the development work first to make sure that we had that support in the community, otherwise you would potentially be putting people in the extremely vulnerable position of being in the community without the right support for them.

Q18 **Chair:** We will hear from the people who are responsible for implementing Transforming Care in the next evidence session. I suspect one of the things they will say is that they have actually been quite successful in placing people from in-patient units in the community, but the overall numbers have gone up because new admissions have continued at a higher rate than anticipated. From that point of view, you need something to make sure that there is community provision for the new admissions as well as for the people who are currently in such units. Is that the case?

Dan Scorer: What we need is the right support in the community to stop people entering crisis in the first place. We need early intervention and support for people and their families so that we do not get anywhere near crisis situations. It is because of a lack of investment in specialist support in the community that many people reach that stage. We need a strategy of investing in community services and support to make sure that a new generation of people do not go into those in-patient settings, as well as creating housing and support options for people to return to the community.

Q19 **Chair:** The original target for reducing the number of in-patient beds for people with learning disabilities and autism by between 35% and 50% by 2019 was missed. It was then replaced with a new target of a 50% reduction by 2023-24. Do you think that we are likely, on current trends, to hit that new target?

Dan Scorer: That 2019 target was replaced with a 35% target by March 2020, which was also missed. At the moment we are currently at around 29%, so we have not even got anywhere near the target from March 2019. No, there are serious concerns that the 50% target for March 2024 may not be met. Certainly, the history of missed targets and broken promises has left people with learning disabilities, people with autism and family members deeply worried that the transformation that we have already talked about in the development of specialist services in the community is not happening at the pace that is needed. We now have a situation where, across the country, in some areas there are those services and in many others there are not. It is a real lottery whether you will get the right support in the community or will be able to come out of an in-patient setting and go back to your local area.

Q20 **Chair:** I want to ask Vivien Cooper about prevention. Given your experiences with Daniel, do you think we need to do more to prevent challenging behaviour from deteriorating into something much worse? Tell us what your experiences are.

Vivien Cooper: Prevention and early intervention are principles that apply to everyone. My experience with my son, which is reflected by lots of the families that contact us at CBF, is that a lot is known about who is likely to develop difficult behaviours, but the information is not used to target early intervention and support.

We asked some academics to look at population-based studies. They concluded that, by the age of three, it is possible to identify that children with learning disabilities are at increased risk of developing challenging behaviour, so there is an opportunity for us to provide the right support for those families and for those children, but in practice what happens is that the behaviours escalate. The approach, as other people have already said, is often one of containment, and trying to contain the behaviours rather than addressing what they are telling us. The behaviours are telling us that there is an unmet need, and we need to meet that need.

There is a range of things. It might be a sensory need. It might be pain. It might be a tangible thing. When my son was little, he had a range of behaviours, and one of them was head banging. He would bang his head very hard on walls and surfaces. We needed to understand the reason for that rather than just trying to stop him. The system, and we at the time, were just trying to stop him, because we did not understand why he was doing it. What we needed to do was to find the underlying reason and cause, and then address that.

My son is non-verbal, so he needs good communication skills. He needs to be able to communicate to us if he is in pain, is hungry or if something is not right. That did not happen. He went through the local special needs education system and they operated containment. It was only when he went nearly 300 miles away to a specialist residential school that they looked at the behaviour, understood what the function was and equipped him with a range of tools to meet his needs.

The system channels you to a route that you do not want to be on, which is a route of exclusion, restrictions, taking things away and limitation. What we need to do is to understand the person and what their needs are, and meet them as soon as possible. Lots of the families that we support can say that things are starting to happen or that they need additional support. One of the powerful things from Winterbourne View was that Simon’s mum was able to say that her son, Simon, was living successfully in the community and just needed a bit of extra support. It was not forthcoming because of funding and all those sorts of things, and he was channelled into an assessment and treatment unit that clearly could not meet his needs. It did not provide him with any benefit whatsoever.

There is a thing around early intervention for age, but there is also early intervention in emerging issues and problems. Alexis spoke about how, when she was beginning to struggle, she could not get the support she needed. It was all or nothing. You cannot get the support you need, so you end up somewhere that cannot meet your needs. You do not end up there because it is the right place to be; you end up there because there is no alternative. We need to put the alternatives in place much sooner. That will stop the ridiculous situation, as Julie explained, that a person has to get to a crisis and go through a system that damages them in order to get out to get the support they need. That does not make sense on any level.

Q21 **Dr Davies:** I have a couple of questions for Ivan Olbrechts. I was speaking to a self-advocacy group for those with learning disabilities in my constituency back in October. Of course, there is a pandemic currently, but isolation was one of the key issues that came through as a problem in what was articulated.

When we look at the 96 locked wards across the country, I am aware that many in those facilities are many miles away from home. Can you give us an idea as to how far away some of those patients currently are?

Ivan Olbrechts: I cannot explain how far some people are, but what I would say is that it is never in somebody's best interest to be a long way from their family. The courts usually pick up the clinicians at some point after some sad event around that particular issue. I fail to see how it is ever in somebody's best interests to be a long way from home. Everybody is saying the same thing here. It is loud and clear, as it was in the Transforming Care programme; the provision needs to be closer to people's homes, otherwise it is not community provision.

Q22 **Dr Davies:** Understood. But there are people on the opposite side of the country, for example. That is my understanding.

Ivan Olbrechts: Yes, absolutely, but I do not have sight of that.

Vivien Cooper: We are supporting families whose relatives are placed long distances from home. That means not only that the person is picked up and put somewhere in an unfamiliar environment by people who do not know them, but that their families struggle to maintain the contact that they want to maintain. They often travel for hours and hours to visit their relative and then come up against other barriers. For example, we have supported families who have travelled for hours to see their relative. They get there and the service will say, "He's having a bad day; you can't come in to see him today." They are denied access.

Conversely, lots of families are told that, if they visit their relative, when they leave their relative is upset, understandably because they want to be with their family. The relative is upset and therefore their behaviour escalates. Therefore, the service tries to restrict visits for families. At a time when it is important that families are involved and engaged, and seeing their relatives, advocating for them and providing all the love, care and support that they do, it is very easy to restrict that and try to cut families off from their relative.

Julie Newcombe: I want to put that on its head. Most of the time, in four of the five hospitals Jamie was in, he was actually quite close to home, about a 45-minute drive. That meant I could visit him every day. I could go and see him every day, and I took him out every day for a couple of hours. We would go to a farm because he likes the animals. We would go out for a Costa. We would go shopping to buy him stuff for the ward. We were out and about in the community with no problem. He had a great relationship with the lady in the local Starbucks. It was just me and him out and about in the community for a couple of hours each day. Then he would go back on the ward and I would get reports of restraints and over-medication, and that he had been in seclusion that morning, and whatever.

That just goes to show the usefulness of being close to home. If I had not been able to do that, I would not have been able to work as hard as I did to get him out. I would not have been able to work with him to provide strategies that made it easier for him to cope and get out, because the staff just could not do it. He might still be there; he might still be in hospital. There was talk about him being sent to secure wards and all sorts. Yet the fact that I was able to take him out every day by myself with no problem whatsoever proved to my mind just how wrong the hospital environment was. It goes to show, if you put it on its head, the usefulness of being close to home and having regular family contact.

Q23 **Dr Davies:** Indeed. Dan, we have heard about Italy, but in terms of what already exists in this country, can you point to areas of good practice? I understand there is a specialist hospital being constructed in the Mersey region, for instance.

Dan Scorer: That's right, and there are huge concerns about it. As you know, we had a service model published by NHS England back in 2015, along with the "building the right support" strategy, which clearly stated what should be developed around high-quality local support services. What is being developed on Merseyside is not in line with that.

Many of us have been asking serious questions about why it is being allowed and why the Care Quality Commission is willing to register a service that does not comply with the service model. It is not what we want to see developed, and it goes completely against the direction of travel that we have had for the last 10 years, of trying not to support people in settings far away from loved ones and family members, where they are at increased risk of abuse and neglect if families cannot regularly visit and find out what is going on. We want people to be part of their community, and that will not allow for that.

Q24 **Dr Davies:** That is very disappointing. Even the latest developments are not meeting demands or needs, as you would see them, in any respect.

Dan Scorer: I think there are major problems. A number of independent providers have been able to significantly expand their in-patient provision under existing regulation of those services, because the CQC is not able to stop expansion under an existing service licence. That is a major problem. The commission needs robust powers to stop that kind of expansion and to make sure that we deliver the specification that was set out in the service model six years ago by NHS England, which everyone supports, around development of local services.

You are absolutely right. In many cases, things are actually going in the wrong direction. New large services are being built that are completely against the service model.

Vivien Cooper: I support what Dan said and I want to highlight the role of commissioners. Commissioners are buying places in the wrong sorts of places with the wrong model of care. They have a huge role to play in commissioning the right community support to meet individual need, rather than purchasing places in the wrong model of care where there are vacancies. There are huge concerns around the lack of accountability. They do not have a professional body. They do not have a code of conduct or standards, and there is no accountability. There are still over 2,000 people in in-patient units, and someone is paying for those beds. Those are commissioners who could be commissioning alternative provision.

There is a range of issues. We do not want people building units, because if they build them people will buy beds in them. We need all parts of the system to work properly. We need the providers not to build the wrong services. We need the Care Quality Commission to register the right services. We need commissioners not to buy places in services that are harming people.

Julie Newcombe: Sorry, you can't stop me when I get going on this. I just want to let you know—although you probably already know—that, talking about the law and legal changes, we have a huge amount of law that is already completely disregarded by authorities, public bodies, commissioners and everybody.

For example, the Care Act already requires commissioners to provide the right kind of support in the community and to shape the market so that that is provided. It is already a legal requirement, but it does not happen. All the other laws get disregarded, such as the Equality Act and the human rights aspects of the Mental Capacity Act, the Mental Health Act and the Children and Families Act. There is huge disregard for the law already out there. We need to find a way of holding people to account when they do not obey the law.

Q25 **Barbara Keeley:** Given what we know and what people have already said, we should thank Alexis for her evidence. It must be traumatic. Every time someone like Alexis talks through that situation, it is potentially re-traumatising. She reminded us so well how bad things could be in an ATU.

Given that clearly everyone on the panel must agree that they are not the right place for people with learning disabilities and autistic people, could we talk some more about what the alternatives should be? We started on that with Viv and Julie, but could you talk to us more about it? What would high-quality, community-based support look like for people being moved out of ATUs? As Dan touched on, it is not there at the moment. What would we have to create to make it work?

Julie Newcombe: I am doing it now with Jamie. We have a Transforming Care grant to buy and renovate a house. That is happening now. We have a very small, values-led, not-for-profit care provider lined up who is wonderful. That is the sort of thing that we are going to need for a lot of people; they will need bespoke packages.

When it comes to care for the individual, again, as I said earlier, we need to ask people what they want and what they need. We also need to say that there will have to be fairly bespoke and fairly imaginative kinds of provision. There are pockets of good practice in the country where that happens, so, to my mind, there is no excuse for not doing it everywhere if there are pockets of good practice. It all boils down to the attitudes of commissioners and local authorities and how they perceive the people who are in hospitals, and whether or not they are prepared to think differently in order to provide the kind of care they need.

We also need community teams. As Alexis said earlier, £5,000 would have paid for some psychology, some OT and some speech and language therapy. That is the kind of thing we need to be getting local, so that people get the help they need from professionals who know what they are doing. A lot of this is psychiatry led. My view is that it should be psychology led. It should be therapy led. It should be trauma-informed support led. It should not be medical led.

We also need crisis care in the community. There has to be recognition that people will, from time to time, hit a crisis. My view and that of many people is, as I think Alexis said earlier, that we need small, local crisis beds, not big hospitals, and community crisis support teams that can either go into the person’s home and help there or, if the person needs to go somewhere else, perhaps to their family, to help them, so that support teams can get training and have a break, and the community support team can support the person in a single occupancy or crisis bed. That is the kind of thing we need. The key to all of it is small and local.

Vivien Cooper: I agree with all of that. My son lives in a bungalow on his own because that is what he chooses and what he needs. The environment is adapted for him. He has his own support team. All the team know him really well. They are highly trained and have all the right skills to support him. Those are the sorts of things that need to be in place. As Julie said, it should be alongside access to community teams as and when needed. They need to be as and when needed. It should not be that you have to go on a waiting list so that in six months’ time you might get some support. It needs to be ongoing.

Most individuals with complex needs will need ongoing support. It might be quite light touch at times, but it needs to be there and available when it is needed. There are some good examples. There has been some work in Ealing and Bristol working in that way with children. Support can go in when it is needed, either in the person's home or in a place where they can go that is not shared with lots of other people who are in crisis, and where needs can be assessed and things can settle down. Support can be provided, but in order to make it happen we need individualised houses for people to live in. We need good support staff and a workforce that is trained, skilled and supported.

My son is supported by staff who are very skilled. They have to understand behaviour. They have to think proactively all the time rather than reactively. All of those things need to be in place, but there needs to be a will to do it. There needs to be a will to invest in making it happen. We need a change in mindset. There seemed to be a mindset when Daniel was little, and I think it is still there now, which is, "Where can we put these people?", as opposed to, "How can we understand these people's needs and meet them?" Too many people have the mindset: "Where can we put these people?", or, "This person is being difficult; we've got to fix them." That is a mindset across a whole range of people. It is a cultural issue.

Q26 **Barbara Keeley:** We are hearing about some of the barriers to that. It is important, given the missed targets and broken promises, which Dan referred to earlier, that we reflect on the barriers. What is stopping that happening? Vivien, you just mentioned the will to do it. Given the will to do it, what are the other barriers that you or other families have run into?

Vivien Cooper: There are a number of them. When my son was born, I thought there was a system that would swing into action to support us as a family. I quickly realised that there was not, and that there is not one but multiple systems and they are not seamless. Navigating your way through a complex system is difficult. Because of how the systems are set up, and because of their funding arrangements, it makes it very difficult to be person-centred.

There are still perverse funding incentives that were identified way back after Winterbourne View. My son lives in supported living funded by social care. If he were sectioned and sent to an in-patient unit, all the bills would be picked up by health while he is in there. In order to get him out, they would have to be picked up by social care. There are all those perverse funding incentives in place.

The whole early intervention approach means that one part of the system has to invest funding to save money for a different part of the system. All the time that is happening, and all the time they are just looking at one-year budgets, it is problematic. My son has lifelong needs. We knew that when he was a child, but even so there was a cut-off point at 19 when everything changes and you have to adjust. Everything goes into a different system.

Q27 **Barbara Keeley:** Julie or Dan, do you want to come in on what the barriers are? It would be good to have a sense of what high-quality support might cost. Julie, you touched on the things you are doing, including with the Transforming Care grant. Would you like to talk us through what the costs could be?

Julie Newcombe: Obviously, housing is going to be a cost, as well as adaptations. That will vary depending on where you are in the country. Housing is key; it needs to be adapted to make sure it is safe. The way I look at it is that it is future-proofing. We want to put things in place in Jamie's house that mean that, if he goes into crisis, he can stay there.

Staffing depends on how you do it. You could get a personal budget and recruit the staff yourself, or you could use a care provider. Care providers, depending on the level of support, could be £3,500 a week for two-to-one support, or maybe a bit more. If you need night-time care as well, it may go to about £4,000. Again, it will be different. We are in the south-east, so it is more expensive.

The important thing to remember in all of that is that it may cost more money up front when you are getting people out of hospital and dealing with those traumatised individuals and giving them the kind of help that they need, but in the long run you will see those levels start to diminish as they start to lead meaningful lives. In the long run, it will start to be cheaper. We see over and over again that support levels decrease.

If you do not mind my saying, Barbara, I find that one of the perverse incentives to moving on is that 50% of the beds that hold autistic people and people with learning disabilities are in the private sector. I genuinely believe that there is a perverse incentive for them not to discharge their patients because that is money lost. I strongly recommend that the Committee read a report about that called "A Trade in People" from Lancaster University.

The other issue is that they see people as a risk. There is a big risk model and a lack of willingness among some responsible clinicians to discharge people because something might happen. Something might go wrong, and then it will be their fault. Not only have you not got the right community services in place, but you have a certain risk-averse attitude in the hospitals themselves.

Dan Scorer: There are many families we have worked with where the in-patient settings where their loved one has been charge upwards of £10,000 a week. We have to remember that a vast amount of money, about £0.5 billion a year, is going on buying the wrong kind of care. At the moment, that money is locked up in the system buying the wrong kind of care. That is why it is so important, as others have touched on, that we have investment up front to develop the community services that are needed to be able to close those beds permanently and release those resources for long-term investment in the kinds of services that we want to see.

We have to remember that in previous programmes, such as the closure of long-stay hospitals for people with a learning disability or the closure of NHS campus sites, going back into the 1990s, that money was made available up front. We have not seen the investment that is needed yet. Although we have NHS England leading this work, without local government and social care being well funded and playing a key role, the NHS alone cannot successfully deliver the programme and transform care.

Q28 **Barbara Keeley:** You talked about the dowry system with earlier initiatives. I remember that when I was in local government social services there was a dowry system for people being discharged from long-term mental health institutions. You are right to say that local authorities are strapped for cash at the moment, so how could we transfer resources? What would it take to get appropriate community-based support in place so that we could discharge from ATUs? Clearly, it is not just a question of the NHS saying, "Here's the budget," because we know there are some up-front costs.

Dan Scorer: An infrastructure has been put in place. We have Transforming Care partnerships set up around the country, bringing together local authorities, NHS specialist regional commissioning and CCGs, to plan and develop the services that are needed, and to work on bringing people back to local areas. What we do not have is a sufficient level of transparency around the work and plans of those Transforming Care partnerships, especially now, if they are to be merged into integrated care systems. There is a real danger that the focus on this area of work could be lost, and it needs to be maintained.

We have had some Government investment. We have the community discharge fund of around £75 million over the next three years, which is to pay for the double funding we talked about, whereby a staff team needs to be recruited in the community at the same time as the person's discharge is being planned, but it is very unclear whether that amount of money is actually sufficient to build support in the community for the number of people who need to come out over the next three years. There are very significant questions. At the same time, we are waiting for the Government to publish their long-expected funding reforms around adult social care, which are desperately needed.

Q29 **Laura Trott:** Dan, we have heard some very powerful testimony today about how in-patient settings are absolutely not the right ones for individual cases. Are there cases that you have come across where in-patient settings are the right answer for individuals, or maybe the choice of individuals or their families?

Dan Scorer: As Julie said earlier, not every in-patient setting is the same. Certainly, with most of the families that we have worked with, if they thought an in-patient setting was going to benefit their loved one and produce positive outcomes, it very soon became clear to them that that was not the case.

That is not to say that every in-patient setting or service provider has the wrong kind of service. There are examples now of new kinds of services being created that are much better suited to meet people's needs. In the evidence today, we have covered very clearly exactly what is the wrong kind of service. We are talking about people being kept on noisy wards and locked in seclusion or kept in segregation. Those are the kinds of practices that we want to see end, and which the Care Quality Commission and others have comprehensively documented over the last few years. We need services whereby, in a time of crisis, people can go to a place where they can be safe, where assessment can take place and where strategies can be put in place if they are living in the community. As Julie outlined, we need to support the staff team and give families respite so that people can return home.

What we do not want is what is happening at the moment, where the average distance that people are being sent is 60 miles away from home, breaking family ties, breaking community connections and making it very difficult for the person to come back to their local area.

Q30 **Laura Trott:** I thought one of the things that Vivien said around person-centred care was really important. Do you think we are underplaying the role of choice in all of this, in terms of choice for the individuals and their families?

Dan Scorer: The wishes of the person should absolutely be at the centre of care planning. That should be where we start. At a time of crisis, it may be that it is determined that the person does not have capacity to make decisions about where they are to go, and they could be placed under section, as we have talked about, and many people are. The basis where everything should start, as Viv outlined, is working with the individual to build a service around them, their needs and interests, where they want to be and how they want to live, whether that is alone or with other people in a small setting.

Q31 **Laura Trott:** In terms of a small setting or a group setting and the CQC powers, obviously it is not working at the moment in relation to the inspection regime. In your mind, what needs to be done to change that so that it has more effect and to ensure the high quality of care we need to see across the board?

Dan Scorer: It has been recognised now that in-patient settings like the ones we are talking about are inherently high risk. Undoubtedly, over the last few years, the CQC has significantly stepped up the way it inspects those settings. We have seen a large increase in the number of them that have been rated inadequate.

The very serious situation we face now is that commissioners are continuing to buy places in services that the CQC has rated inadequate. That is clearly not acceptable. If a service has fallen to a level where there are major concerns about safety, leadership and person-centred care, why is it acceptable for people to be supported somewhere like that? There are very serious questions that have to be asked now about what happens when a service is found to be in that situation. Whether it is Winterbourne View or Whorlton Hall, we know the risks that are there and that abuse can lie undiscovered.

Laura Trott: Putting in clear guidance that no services should be commissioned in a setting that has been deemed inadequate seems to be a very sensible change.

Julie Newcombe: To add to Dan's points, the CQC cannot close inadequate hospitals if there is nowhere for people to go. It has actually said that. There are places that are deemed inadequate, but they have to stay open, with all their abusive practices, because there is nowhere for people to go.

Q32 **Chair:** Let's move on to another very important issue, which is the use of restraint, seclusion and sometimes over-medication in in-patient units. I want to ask Julie from Rightful Lives about the situation today.

We were all very shocked by what happened at Winterbourne View in 2011 and the infamous BBC *Panorama* documentary. That programme detailed evidence of residents being assaulted by staff, restrained harshly, given cold showers and left outside in freezing temperatures as punishment. You campaigned really hard after Jamie went through similar abuses. Ten years on from Winterbourne View, in your view, are things improving?

Julie Newcombe: It is important to say at the beginning that there are pockets of excellent practice that prove that people can lead really good lives. We need to hold on to that. Outside that, no, I do not think so at all. The 2020 CQC "State of Care" report said that the number of private sector learning disability and autism wards rated inadequate rose from 5% to 22% year on year. That is saying that things are getting worse, or that the CQC is getting better at inspecting.

The recent thematic review reported that there is a particularly high incidence of restraint and seclusion of autistic people, which would indicate that what we are seeing is a poor understanding of autism and how autistic people show that they are distressed. Again, we need to remember that this group of people have a very specific set of needs.

In all the campaigning work we do, and from all the families we talk to, we still hear about abusive practice, broken limbs, endless hours in bleak segregation cells, bullying, gaslighting and over-medication. People are left dirty and hungry, and families are threatened and sidelined. Some people were too frightened even to come and give evidence to you today because of the fear of reprisals.

I gave evidence on this over two years ago to the Joint Committee on Human Rights, and I do not think anything has changed at all. In my head, that means people think it is acceptable. People know what needs to be done. They know what is happening. They know what needs to be done to stop it, and still nothing happens. In my head, that means it is acceptable. I would really like to know why people think it is acceptable.

Q33 **Chair:** We have been talking about the long-term solution at quite some length in terms of moving to a community-based care model. Julie, are there specific changes in the law that we should make so that seclusion and restraint only happen in the most exceptional situations?

Julie Newcombe: We are still waiting for Seni's law. It was approved by Parliament two years ago, but it has not been enacted in law yet. First of all, we need to start doing that and make sure that it gets made into law.

It is about monitoring it. I would certainly agree that we change the law so that it only happens in exceptional situations, but it is monitoring it. We already know that a lot of hospitals do not always report all the incidents of restraint and segregation that they are supposed to report. The numbers are probably higher than you see in the reports. Yes, change the law, but make sure that you monitor it as well.

Q34 **Chair:** Let me bring in Dan Scorer and Ivan Olbrechts on this. Most people accept that there are exceptional situations when, for the safety of staff and residents, you have to use those techniques. The concern, and we heard it earlier from Alexis, is that it has become a normal way of treating autistic people or people with learning disabilities in certain settings.

Do you think that, with the changes to the Mental Health Act that the Government have announced, we should make it a requirement that such techniques can only be used in the context of a proper, approved programme and in adherence to standards on how to reduce conflict, so that they are genuinely a last resort?

Dan Scorer: Yes, that is a very important point. As we touched on earlier, what we need in the community and, of course, in in-patient settings now, because they are going to be with us for some time, is understanding of learning disability and autism, and understanding that that environment triggers behaviours for people. It creates a vicious cycle; the inappropriateness of the environment leads to behaviours that are clamped down on with the use of restraint, chemical restraint, segregation and seclusion.

The work the CQC has done has been very important in shining a light on that, and showing that it is system-wide and needs to be tackled urgently. We await the Government's response around the measures that they are going to put in place to address those unacceptable practices.

Q35 **Chair:** Ivan, the Secretary of State has said that he wants to change the way that people with learning disabilities and autism are referred to under the Mental Health Act, so that there is a more targeted approach that reflects their own situation. Do you think this is an opportunity to change the legal structures behind the use of techniques like restraint and seclusion?

Ivan Olbrechts: The CQC already has the powers to request information from providers. I am not sure that it actually has line of sight of all of the uses of restraint. Perhaps a starting point would be making sure that it can actually see all those instances, and that it receives reports and can monitor, react and decide how to inspect and respond to them. It can then pick up on those practices. That line of sight is within its existing gift.

Under the Mental Health Act changes, I welcome the stipulation of therapeutic benefit, but I fear that the repeated requirement from the 1983 Act that appropriate care and treatment is available will continue to be the crux of the matter. We have all spoken about that today in terms of what is available in the community, which is where it needs to be available. That is my fear with the Act. I am particularly pleased that it was developed with people with lived experience. I fully support the four guiding principles outlined. That is lovely, but the crux will be that appropriate care and treatment is available. That is the problem we are talking about today.

The Transforming Care programme provides a perfect solution, except that it is another challenge for a provider and for a family in trying to get somebody discharged. The argument is not only whether it is available, but whether it is to the satisfaction, effectively, of the multidisciplinary team that will decide whether it meets their requirements. That is an additional barrier, besides the funding one. It needs to meet the technical and therapeutic requirements that the people in institutions apply. You have to satisfy their values and their judgment, when we know that they are doing it wrong. Go figure.

Q36 **Paul Bristow:** I have a quick question for Dan. You say that the Government are planning to respond to the CQC report. What are the top three things you would want to read in that response?

Dan Scorer: The No. 1 thing we would want to hear from the Government is what they are going to do to tackle the unacceptable use of a range of restrictive practices. On one hand, there is the use of physical restraint, including prone restraint, which is extremely dangerous and should only ever be used very briefly in the most exceptional circumstances, but we know that is not the case. It is used in a far more widespread way. Then also, what they are going to do to tackle—

Q37 **Chair:** Dan, could you explain what prone restraint is for anyone who is not aware?

Dan Scorer: It is when a person is restrained with their face towards the ground, potentially with numerous staff members around or on top of them. In terms of highlighting cases, we have seen multiple examples of footage where you could have 10 staff members restraining one person. We have heard of examples where people have been restrained for an hour or more in that position, which is extremely dangerous.

As well as that, there is the use of chemical restraints, where people are given anti-psychotic medication when they do not have a mental health diagnosis. That is often something that is used to manage behaviour or stop behaviour rather than, as Viv outlined earlier, understanding behaviours and their triggers, and supporting people with those.

It is also about looking at the use of long-term segregation, where people are kept away on their own, or indeed seclusion, where they are locked away in cell-like conditions, which the CQC has documented.

Q38 **Paul Bristow:** Let's hope that is in the response. I want to look back to the previous section. Vivien talked about examples of best practice in Ealing, Bristol and other places in the country. What was the catalyst to drive those examples of best practice? What was in place there that allowed those best-practice examples to emerge?

Vivien Cooper: I think it was individuals with vision, determination, skills and knowledge. Behind every pocket of good practice are probably one or two individuals who are determined to do the right thing, almost despite the system. It was individuals who took the initiative and suggested a way forward. They then piloted it and proved that it worked, and carried it forward.

Q39 **Paul Bristow:** It was the culture of the particular individuals driving the team. Something I am interested in is that sometimes the NHS and social care system can be guilty of not learning from best practice and have to repeat it in every single location to prove that it works before it gets adopted. How can we change that? What do we need to capture, for example, in Ealing, Bristol and other places to demonstrate that it works? Is patient experience the right metric, or are there other metrics we can capture to demonstrate the validity of the approach?

Vivien Cooper: I think they have captured some evidence. We put in our evidence paper that there are financial savings and benefits to individuals, and so on. I think there is an assumption that if there is a pocket of best practice, if you write a short paragraph about it and make it available, it will just happen. We have proved over the last 10 years that that does not work. Change has to be taken, driven and implemented, with people helping people to do it. I think that is what is missing. We have all talked today about the issues. They are well known and well documented, and they are in numerous reports, but at some point someone has to do something. It is the doing that is not happening.

For Transforming Care there was acceptance, after Winterbourne View, that there are multiple parts of the system that are ineffective and damaging. It needs to be transformed, not tinkered with around the edges. That means that all the different parts of the system have to be transformed in a way that is co-ordinated and coherent, to ensure that all the interconnected parts are connected because there are so many interdependencies. Until someone has that overview, has grasped that and has a way of driving change forward, I do not think care will be transformed.

Q40 **Paul Bristow:** Finally, do you feel that a system where we commission for outcomes would help to transform care?

Vivien Cooper: Yes, I think it would. There are so many initiatives that have started and are often well intentioned, but it is almost like we get hung up on the process and forget about the outcome. There is a real need to focus on individuals: "What difference will it make to this individual's life if we do this?" It would be really helpful to think about an outcomes focus.

Q41 **Dean Russell:** I would like to ask Dan a couple of questions about community, but also about society, with regard to attitudes and how they have changed. In the first instance, I want to understand the main challenges you see to ensuring that people with learning disabilities and/or autism are moved from the in-patient setting back to communities. I know that you wrote to Sir Chris Wormald about this previously, and the challenges of that.

Dan Scorer: If we look at the monthly data that is published by NHS Digital, showing us the situation in terms of the number of people still in units, and if we look at delayed discharges—people who are ready and waiting to come out and back to the community—the two top reasons for those discharges being delayed are lack of housing options and lack of community support.

One of the welcome things the Government announced in the recent manifesto was the community discharge fund, which is an additional £75 million over three years to double-fund services. Where a service is being developed in the community and a staff team needs to be recruited, that can happen at the same time as the person is in an in-patient setting. There are two things for which the money is there. One is for paying when the person is in a unit, and the other one is for the community service.

What we wanted to know in writing from Sir Chris Wormald, the permanent secretary at the Department of Health, is what plans local areas are developing to use that money, how they will be held to account for the successful delivery of those plans and how we will know about the difference it is making to people's lives. That was what we wanted to know.

From the response we had, we are not yet clear that the amount of money that has been allocated is sufficient to deliver the transformation that we all want to see in the development of the community services. One of the key questions we were asking the Department is what assessment was done to make sure that the money being offered is enough to bring about the development of the community support that we all agree is desperately needed and want to see.

Q42 **Dean Russell:** Did you get a response to that?

Dan Scorer: Yes, we did. We want to have further discussions because we want robust local plans put in place to spend that money, to make sure that it makes the difference that is needed to people's lives. At the moment, I do not think we have the evidence that we want to see for that, so we are going to continue pushing on it.

Q43 **Dean Russell:** My next question is a much broader point. It is about society. Over the past few decades, when we look at learning disabilities, autism and anything to do with mental illness, as much as mental health in the broadest sense, there still seems to be a stigma around that in communities. I have an inspiring local constituent whose son has been attacked at train stations because there seems to be fear in society around anyone who is different, and in particular for this particular group. Do you see things getting better? When we look at the community in the widest sense, is more needed to educate people and reassure them, to open up those conversations?

Dan Scorer: Yes, I think it is. It starts from a young age. We want our children to be educated together. Where we have inclusion in mainstream schools, and disabled and non-disabled children grow up alongside each other, the concept of difference is not there. Difference is accepted.

For so long, looking back to the last century, people with a learning disability were locked away in institutions, as the group of people we are talking about today are still locked away in institutions, except they are not Victorian asylums but in-patient mental health settings. Much more needs to be done to raise awareness and understanding. It is not just in society; it is among our professions as well, whether it is tackling the health inequalities that people with a learning disability face or struggling to get the right support in hospital.

Raising awareness and understanding is absolutely vital to breaking down fear and lack of understanding, which can lead to things like hate crime, whether that is violence on the streets or the hostility online that many people face. When people grow up together and live alongside each other, there is much less chance of that violence and hostility being allowed to continue.

Q44 **Dean Russell:** Do you think that feeds into some of the decision making about releasing people with learning disabilities, autism and so on back into the community because there is that fear, or is it just one of those things?

Dan Scorer: I think it does. We touched on it earlier. Clinicians and psychiatrists who have the power to continue people's detention or to release them into the community may often have a perception of the risk that they think that person may pose if they go back to the community.

We are saying that the way people are treated in these in-patient settings and the environment they are in is not remotely representative of what they need. We have worked with many families where, literally the next day, the person is out in the community, with support but absolutely fine and enjoying themselves, whereas literally days previously they were being restrained by numbers of people and locked away in a cell. Clearly, what we are talking about are problems with environment and support and not with the individuals, who can be supported and lead fulfilled lives in the community.

Q45 **Rosie Cooper:** I have listened very carefully to what has been said today. What I draw from it is a huge sense of frustration that between Winterbourne View and the 10 years to Whorlton Hall, there has been lots of talk and promises with everyone acknowledging that change is needed, and that we need a change of law prohibiting seclusion and restraint except in exceptional circumstances. I would like to ask whether the panel are confident that the CQC inspections are identifying the cases where the use of restraint and solitary confinement risk breaching human rights. When they do, does the CQC have sufficient powers to address those issues? If it has, why do they keep happening?

Ivan Olbrechts: I think I mentioned a little earlier that I think the CQC has sufficient powers. It can inspect every inch of the hospital. It can impose conditions and even close a hospital. It can do the same to the community providers. It can even inspect inside people's own homes, so it has the powers. It has the power to request information from providers. I am not sure that it has that line of sight for all of those institutions, so maybe there is a lot more it can do in that area.

I believe the CQC has a memorandum of understanding with the GMC and other professional bodies. I would observe, for instance, that the care workers jailed after Winterbourne View were not actually the people who signed off the Mental Health Act decisions. Perhaps if the Committee asks the CQC a question, they might like to ask how many times it raised concerns about a responsible clinician or other professionals who were signatories and parties to those issues in the institutions.

Q46 **Rosie Cooper:** That is a really valuable contribution. How do we help to find out what is going on? How can we make it easier for families to report worries that they have about the way their loved ones are being cared for? People are frightened. My parents were born deaf, and they never wanted anybody to complain because they would be picked on. It is endemic. How do we strengthen people to speak up?

Ivan Olbrechts: I am very pleased to have been included in a CQC group that is looking at closed cultures. My mother passed away in a mental health institution with Covid last year. I did not know she was there. I could not find her, partly because of the system. I had lost touch with her for a long time, and one of the reasons I could not find her was because she was in the system. I identify very strongly with people who have family challenges that are defended by the system. There are some ongoing things about that as well.

Again, it is part of the closed culture discussion. We are saying that it is absolutely a risk factor and that the inspectors should ask more in an inspection and should delve a lot deeper when they find there is not enough involvement. That needs to be tested a lot more severely in inspections when they find there isn't active family participation because when dad visits there is an escalation in behaviours.

When dad has had to travel 200 miles and can only come up on the weekends, I would expect that may well contribute to some behaviours. I do not think it is ever in anybody's best interest not to have family involvement in one way, shape or form. It tends to be better defended by the courts, I have to say, than it is by the professionals. That is what we find if we go to the Court of Protection, for instance.

Q47 **Rosie Cooper:** Thank you. Dan, we spoke earlier about the 40-bed unit at Mersey Care and the general view that it is right to keep people out of hospital. I absolutely agree with that. Have you had contact with Mersey Care about the client group? I may have some of this wrong, but I doubt it. The reason I ask is that I understood it was a forensic service and it would offer a service to people with learning disabilities who were in serious trouble with the justice system—not minor crime, but pretty serious stuff—and who may or may not have other comorbidities. The likely alternative for those people would be imprisonment—jail—so surely that unit would be a better setting for them to receive care. I would like your view. What would you suggest we do in this case?

Dan Scorer: We need to go back to the history. It is all about the reprovision of the Calderstones site, which was the last learning disability trust, and the restructuring of services across the region. Extensive consultation took place with people with a learning disability and people with autism, family members and other stakeholders across the region by NHS England. The point that is now being made is that this centralised unit is not the model that we should be going for. It is not what people in the region wanted from the reconfiguration of those services. We did not want a large, single regional service that people were potentially sent long distances to. That is not the model we want to work towards. The issue is that many people in the community do not feel that they were listened to through the consultation, and this is not the outcome they wanted.

The point that you are making about the alternatives for people in terms of diversion away from the criminal justice system is, of course, extremely important. We have to reflect, on the other hand, that people who go into prison have a date by which they will come out. They will come back to society, whereas many people with a learning disability go into these units but do not come out. If a responsible clinician deems them not fit for discharge, they will not come out.

There are issues about the large-scale model of the service that is being created and how that is compatible with the service model that NHS England published back in 2015, which was very clear that the national policy drive was to create small, local services. There are worries that it will see people being sent far away from home to a large service, where there will again be concerns about what will happen to them—all the issues around restraint, over-medication and seclusion that we have already talked about.

Julie Newcombe: I would like to add something on the thinking around why people actually get involved with the criminal justice system. To a certain extent, the repeated failure of services over the years is one of the main drivers behind that. For example, if you do not meet someone's needs and you do not provide them with the support they need, it is possible that they will get involved in the criminal justice system. They may be reacting to something like abuse, they may be reacting to not having their support needs met, or they may get involved in crime when somebody befriends them and puts them up to no good. Those can be some of the reasons why people get involved in the system. It is important to bear in mind that, by putting them in a long-stay hospital and not letting them out, we are punishing them twice. We let them down, and then we punish them as a result.

The other thing I would like to comment on is how people acquire criminal records inside these hospitals. I think Alexis alluded to it earlier. They go into hospital and then, because the environment is so alien and so aversive, they react to that. The hospital or staff member presses charges, sometimes asking for compensation, and the person ends up with a criminal record that is life limiting. That is how those involvements occur. When we talk about the criminal justice system, of course, yes, there are some dreadful crimes committed. Nobody is saying they are not, but we need to do a lot of work on how it gets to that.

Rosie Cooper: I will need to do a lot more work on this now, frankly. I understood that it was for serious crime like arson and rape—that kind of level—not the lower levels of crime. I think there is a mismatch between expectation and what we think is happening. I will need to ask questions, as you say Dan, about the length of stay. It is a new unit. I do not even know when it is due to be finished and people will go in, but it is something where the length of stay would need to be monitored. It is also whether they would spend that time there or in prison. It is something we need to look at very carefully.

Chair: The final question this morning is from Barbara Keeley.

Q48 **Barbara Keeley:** Dan mentioned earlier the fact that in-patient provision has expanded. The thing to know about that is that it expanded at a time when the Government target was to cut it through Transforming Care. After Winterbourne View, the first targets were that those units were all meant to be closed.

Do you have concerns that current providers would create provision and call it something other than an ATU or an in-patient unit, but with the characteristics of the current, inappropriate or inadequate provision? Is that a danger? After all, Whorlton Hall was a care home and that was a very abusive environment. Is that something the Committee ought to take into account?

Julie Newcombe: It is already happening. We are seeing private providers build their own residential homes and discharge their own patients to them. This is a big concern for me with the integrated care systems and provider collaboratives that are being developed. The private providers will actually have the power to commission and provide their own care. They can make it look pretty much what they want it to look like. Obviously, the CQC would have something to say about that, but we are seeing residential homes being set up by private providers pretty much as an extension of the hospital. It is another ward.

Vivien Cooper: There is a long history of it, too. After Winterbourne View there were lots of hospital-type provisions changing their registration to residential with nursing to come out of the figures and out of the scrutiny. All the time that a company is in the business to make profit, there will be that conflict of interest.

When my son was little and was going off to a 52-week residential school, a big provider came and tried to sell the company to us. How they sold it was to say, "Your son can come to our school; then he can go to our college; then he can go to our supported living; and then he can go and live in our village." It was a lifelong approach, which was absolutely what we did not want. That is how they think. Their reason for being is to generate profit, and that shapes how they think and what they do.

Chair: Thank you very much indeed. That brings us to the conclusion of this morning's session. I thank our witnesses. We have had a very thought-provoking session in which we have looked not just at the things that are going wrong, but at good practice. We have talked about what happens in other countries. We have talked about what could happen here in terms of changes to the law, both with respect to new in-patient admission and to practices in in-patient admissions such as seclusion, segregation and restraint.

A very big thank you to Alexis Quinn, who gave very powerful testimony right at the start, which created the context for further discussions; to Julie Newcombe and Vivien Cooper for their campaigning based on their own personal experiences; to Ivan Olbrechts, who has a nephew with autism; and to Dan Scorer from Mencap.

Thank you very much for helping to set us off on the right tack in our inquiry. We really appreciate your time this morning.