HOUSES OF PARLIAMENT

Joint Committee on Human Rights

Oral evidence: The detention of young people with learning disabilities and autism, HC 1861

Wednesday 9 January 2019

Watch the meeting

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

Questions 1–12

Witness[es]: **Dr Paul Lelliott**, Deputy Chief Inspector of Hospitals, Care Quality Commission; **Ray James**, National Learning Disability Director, NHS England; **Dr Jean O'Hara**, National Clinical Director, Learning Disabilities, NHS England.

Examination of Witnesses

Dr Paul Lelliott, Ray James and Dr Jean O'Hara.

Q1 **Chair:** Welcome. Sit yourselves down and make yourselves comfortable. As you know, we are the Joint Committee on Human Rights, and we are half Members of the House of Lords and half Members of the House of Commons. We look at all issues concerned with human rights. One of the most important human rights is the right to have your liberty and not to be subjected to inhumane or degrading treatment, or to torture.

This inquiry is looking at the detention of children and young people with learning disabilities and autism. We are very grateful to you for coming to contribute to this inquiry. Perhaps I could start by asking you to introduce yourselves to the Committee and say what your remit is.

Dr Paul Lelliott: I am the deputy chief inspector of hospital at the Care Quality Commission and my role there is to lead on mental health, which includes learning disabilities.

Ray James: I am the national director for learning disability at NHS England. I joined there a little over a year ago and was asked to lead a national programme of change, trying to ensure that we help people to lead exactly the sorts of lives that we would want them to lead in

community settings and have much less reliance on the type of things that you are interested in exploring.

Dr Jean O'Hara: I am a consultant psychiatrist. I work in adult services in the community in learning disabilities. I am currently the national clinical director for learning disabilities at NHS England.

Q2 **Fiona Bruce:** Good afternoon. My first question is to Mr James and Dr O'Hara, and it relates to whether the use of detention is appropriate when we are caring for young people or people with learning disabilities and autism, and whether particular placements are appropriate.

My question is this: 2,350 people are still being detained despite years of commitments to reduce these numbers. Why are commissioning bodies spending millions of pounds to send people with learning disabilities and/or autism to institutions where, regrettably, they have the potential to sustain further harm?

Ray James: We should always begin with what is in the best interests of the individual concerned and would always hope that we can provide the care, support and treatment that somebody might need in a community setting. There may be occasions when somebody needs access to in-patient treatment. When they need access to in-patient treatment, we should try to ensure that it is specifically for the purposes of treatment and only for the period that is necessary to ensure that the treatment is successfully delivered. Collectively, our aim across health and social care would always be to help people to lead as independent a life as possible for them in other settings.

The figure you quote includes adults as well as children and young people in the total. The latest figures in respect of children and young people in England are in the order of 250 to 260. In the situations where it is necessary, it will either be for a period of assessment or to try to identify appropriate courses of treatment for the young person concerned.

It is probably also important to acknowledge that there is a much higher likelihood that a young person with a learning disability or an autistic young person will also have mental health conditions. For example, it is recorded that approximately 70% of autistic children and young people would meet the criteria for having one or more mental health conditions. The treatment may not necessarily be primarily in relation to the learning disability or autism; it will normally be in respect of the underlying mental health condition.

Dr Jean O'Hara: First, it is very difficult to admit somebody into hospital these days. As far as possible, we avoid admission. It is probably useful to say that first.

To my mind, as a clinician, there are four types of scenario in which admission might be appropriate. The first is as in the general population where there is serious mental illness, deterioration or a health and safety

issue for the person, whether it is serious self-harm, an acute psychotic episode or a depressive illness with suicidal ideation. That sort of admission is very appropriate. Then, while the person is in hospital, we understand that they have additional problems, such as a learning disability or autism. That is one group of patients.
The second group is people we already know of who have a learning disability or autism, again who have a mental health issue that is being managed fairly adequately in the community but there has then been a breakdown of some description or an escalation of problems. There is a short-term admission into hospital to understand the issues and to test out various alternative interventions, and then a quick discharge home. That is the other type of admission I would look at.
The third group is admissions from the courts of people who have offended, and they can be very serious offences.
The fourth group is probably the most contentious. These are the people who present with a learning disability and autism but who happen also to present with quite severe, challenging behaviours. From my own training, I know that you do not admit somebody like this if at all possible, because there are a lot of environmental factors that affect how someone presents. Nevertheless, there are times when it is very risky and you cannot assess or treat somebody in the home environment, perhaps because it is impractical or they have younger siblings in the home. When that occurs, the question has to be about the reasons for admission. Then you address those reasons and get them out as soon as possible.
Those are the four groups who, to my mind, may require admission to hospital, but only for specific referral or admission criteria, and with quick discharge.

Fiona Bruce: I have the impression that there are some people in these units for whom the placement is not the most suitable, perhaps the latter group in particular. Do you know how many people are in these units and it is not the best place for them to be?

Dr Jean O'Hara: We know from care and treatment reviews we have done that there are a number of people who those reviews have deemed would be ready for discharge in the next six to nine months. We are working very hard to try to discharge that group of people. They may be a combination; it is very difficult from the data to know which.
Challenging behaviour is a description, not a diagnosis. It is very difficult from databases to pull out that group of people, but we have an idea about the people we could be moving into the community, and that is the cohort we are trying to work with.

Fiona Bruce: You have an idea of the individuals, and perhaps of the numbers or percentages involved.

Ray James: It is really important to look at what happens before admission. The real challenge for all public services across local government and the NHS is what more we could do to avoid the need for somebody to be admitted in the first place. If we can ensure that there is

good joint working in local areas across education, social care and the NHS, it is perhaps the most effective thing we can do to reduce the need for admission in the first place. We would like to think that, in the vast majority of circumstances, appropriate care and support can be provided in other settings.

Fiona Bruce: Some of my colleagues will ask about those settings. Mr James, you mentioned that the number of children detained at present is between 250 and 260. The Committee understands that this has more than doubled from the figure in 2015, when it was about 110. Can you explain why that should be?

Ray James: Yes, certainly. In part, there have been changes to the way in which the numbers are recorded and counted. In particular, autistic young people who receive treatment in mental health in-patient beds are now counted in the current number; they were not consistently counted that way when the number was 110. I do not want to give the impression that I am trying to explain away changes in data due to the way in which the data is collected and presented, but that is a helpful point of understanding.

Particularly in respect of autism, there are a number of young people who first get a diagnosis after they are admitted. They would not have been included in the count at the outset, but they are once that diagnosis is afforded. It is probably helpful to understand that 70% of the overall 250 to 260 number currently have a diagnosis of autism and no learning disability. Interestingly, that figure has been in excess of 60% of the total over the period we have been talking about. That is a clear signal that, across public service, we need to ensure that we keep having more work to develop our understanding of what is needed in community settings in order to reduce the likelihood of those admissions particularly for autistic young people.

Q3 **Fiona Bruce:** My next questions are to the whole panel, so perhaps I will ask Dr Lelliott to answer first.

We have heard that care in institutions is funded by the NHS, while community care is local authorities' responsibility. Would it perhaps not be better if the funding followed the individual in order to allow people to be cared for in community-based settings or at home, if that is best? Might that not also be at a lower cost?

Dr Paul Lelliott: It is certainly true that the funding must follow the individual. That is essential, whether it is achieved by removing the distinction between health funding and social care funding, or by making sure that the two work together in a seamless way.

If I can refer back to another piece of work we did a year or so ago, we undertook a review of children's and young people's mental health care, which was not just for young people with autism and learning disability. One of the main conclusions we reached was the fragmentation of the

system, not just in the multiplicity of providers of care but in the commissioning arrangements, the assurance arrangements and even the regulatory arrangements. When it comes to regulating services for young people, the responsibilities are split between a number of regulators.
Fragmentation and complexity are issues. How do you resolve those? You do that either by getting the parts of the system to work well together or by changing the system.

Ray James: Interestingly, before I joined the NHS, my whole career has been in local government. I had the privilege of serving as the president of the Association of Directors of Adult Social Services a couple of years ago. It is true that, at both the individual level and the local area level, you can make best use of public money by putting it together and having a very clear focus on the needs of the individual.
We have encouraged local areas to pool budgets and provided advice on funding transfer agreements. Even in areas where there is no formal pooling because it has not been possible to reach agreement across local government and the NHS, there are ways to do something akin to open book accounting with a transparent and shared understanding of what public money is being used for. Personal health budgets, personal social care budgets and integrated personal health and social care budgets have made a real difference to the lives of many individuals, and we would support and encourage that.

Q4 **Fiona Bruce:** I have a couple of final questions. Does the current system give private providers a financial motivation to unnecessarily detain people?

Ray James: One would hope that the best interests of the individual concerned were always paramount in driving the decisions that are taken. I have certainly heard family members talk about the potential conflict of interest in situations along the lines that you describe.
For me, it ought to be about where the individual will receive the best quality care and support that they need at that moment in time. That ought to be the determining factor in the choice of who provides the care and support, always with an eye to ensuring that the aspiration is to help that individual to lead a life of their choosing as independently as possible in the longer term.

Q5 **Fiona Bruce:** As a final question, might we be able to radically improve the support that we give these individuals if we had much earlier diagnosis? I just give as an example a mother who came to see me at my constituency surgery last week. She has a young adult son who was referred by his GP for an ADHD specialist assessment, and she was told in the autumn that the waiting time would be over three years. Is this not one of the major problems?

Dr Paul Lelliott: Yes, it is. If I refer back to the review of children and young people's mental health, that was another core finding. Some young people with more common forms of mental health problem wait a long

time for assessment, but for people with more specialised needs, including autism, autistic spectrum disorder and ADHD, we have undertaken inspections where we have found waiting lists that are a year or two years, and sometimes more.

Ray James: It is probably important for me to say that when NHS England published the long-term plan earlier this week, it included a commitment to work towards earlier diagnosis.

Fiona Bruce: Of necessity, that presumably includes training more specialists.

Ray James: Yes.

Chair: To follow that up, are you acknowledging that because there are long waiting lists, as Fiona raised, people do not necessarily get the care and support they need in the community, in their own home, early enough? This then ends up with a crisis. Because there is not a high enough level of support in the community to deal with the crisis, they end up being detained in a residential setting, which then damages them and makes them worse. The ability to get them out is impeded by the lack of support in the community, which makes it difficult for them to get back into the community.

Meanwhile, the financial incentive on the private provider is not to get them out as quickly as possible, because as long as they are there they are an income stream. Is that, in sum, a picture you recognise? You have talked about your intentions, the policies and the aim, but is that a picture you recognise for some, if not all, young people with autism?

Ray James: I would not describe it particularly in the way that you have, Chair, but there is a range of risks in what you have articulated that I recognise and hear talked about.

The point specifically about early diagnosis is this: in order to respond most appropriately to an individual's needs, the better you understand them, and the earlier you understand them, the more effective you are in responding to them. In areas that do this well, they focus work on early diagnosis but they also look at meaningful involvement of the individual and of family members. Their collective contribution to understanding the individual as well as possible in order to provide the care, support and treatment they need is central to beginning the journey well.

To the point you made about crisis, it is true that it may very often be points of crisis that heighten the risk of somebody being admitted to an in-patient setting. We have been clear in the long-term plan that we would expect to see seven-day crisis services in every area of the country. There will be a workforce challenge in ensuring that there are enough people in every part of the country with the skills and training required to respond appropriately, particularly to people with the most complex needs.

To the other issue that you raise of where the money is in the system, we have already this year deliberately moved money from spend on specialist in-patient services up front, some £53 million, supplemented by a further

£22 million of new investment, to accelerate the rate at which community-based services become available in local areas and reduce the reliance on in-patient services.

Q6 **Baroness Hamwee:** My first questions are about inspection. The Chair, understandably, as we are the Joint Committee on Human Rights, introduced this session by referring to the dangers of breaching human rights, including detention and inhumane treatment.

I wanted to ask whether inspections are picking up on cases, and whether there are the powers to do so, where there is the risk of breaching human rights, particularly with regard to restraint and solitary confinement, and in connection with solitary confinement—I am sorry; that is a long sentence—all that that carries with it. One piece of evidence we have heard and read about is of detainees being given their meals through a hatch in a door. I mention that in particular, because it shocked me very much. Are there sufficient powers? Are problems being picked up?

Dr Paul Lelliott: Can I briefly describe the various duties and responsibilities that we have, because they are relevant? First, we are the independent regulator of health and care in England. We have responsibilities under the Health and Social Care Act to assess, register, monitor, inspect and regulate services.

We are also responsible for monitoring the Mental Health Act in England. With that particular function, it is our responsibility to ensure that the human rights of people who are detained are respected.

We have a third set of responsibilities as part of the national preventive mechanism under the operational protocol against torture and ill treatment. So we have three sets of responsibilities, and they all take a human rights perspective when we assess the circumstances of people detained in hospital.

Baroness Hamwee: Are the powers to inspect adequate?

Dr Paul Lelliott: In our regulatory powers, we have the power to inspect. We rate services, but we also have enforcement powers, which are both civil and criminal. They range from making requirements on services to issuing warning notices and putting limitations on a provider's registration. Ultimately, we have the power to cancel the registration of a provider if it fails to meet the regulations. Under the Mental Health Act, we have unfettered access to any place of detention and to people who are detained.

Baroness Hamwee: Do you make unannounced inspections?

Dr Paul Lelliott: Yes, we do. Increasingly, our inspections are unannounced. In the early days, when we took comprehensive inspections, because of the scale of the inspection we would have to announce them. But now a high proportion of our inspections are

unannounced. Mental Health Act visits by Mental Health Act reviewers are fully unannounced.

Baroness Hamwee: When you find that staff have treated patients badly, what data do you have about disciplinary action that has been taken against them?

Dr Paul Lelliott: If we conclude that staff have been abusive towards patients, we inquire very closely as to the measures that the provider had taken to hold that person to account. We have an agreement with both the General Medical Council and the Nursing and Midwifery Council to share information about individual professionals who might have acted in a way that is against the professional code.

Baroness Hamwee: Turning it the other way round, do you think that establishments are keeping proper data about disciplinary action?

Dr Paul Lelliott: That is a question that we always inquire about. We ask not just about the professional and managerial supervision and the training and appraisal of staff but about how performance is managed, which includes misbehaviour.

Baroness Hamwee: Can I ask the NHS people about the other side of the coin and whether commissioning bodies actually use CQC reports? Is poor performance taken into account when decisions are made about placements? I am sure you are going to tell me that they do not just sit on the shelf and gather dust, but I would be interested in digging down a little on that.

Ray James: From my local government and NHS experience, yes, I would expect CQC reports to be used. They are also often one of the most accessible forms of information to family members and to individuals themselves because of the way they are recorded on the public record. You would expect to see good close working between a local authority, the NHS and the CQC, were there any concerns about the quality of care, because there are often situations where a number of different local areas are commissioning care and support with one provider.

Therefore, the liaison is followed through to ensure that other public bodies have the opportunity to satisfy themselves of the well-being and safety of the individual they have commissioned care for. Yes, it should be used. Yes, there should be continuous working and sharing of intelligence where there are concerns. Often, we can respond most robustly and effectively when that sort of information is being appropriately shared across agencies.

Baroness Hamwee: I do not want to be pedantic, but you said that there should be. Is proper use being made of them?

Ray James: Yes, from my personal experience. I have been involved in safeguarding processes during my time in local government where that has been the case, and have seen it through my national role as well.

I have been aware, since I have been at NHS England, although I am less involved in individual packages in that way, of there being clear action in relation to providers where there have been concerns of that nature. That

said, it is probably right to acknowledge that you and we have heard of circumstances that are a very salutary reminder that that would not appear to be everybody's experience. Our challenge is to ensure that that happens up and down the country in a consistent way for everybody.

Baroness Hamwee: We will have a question later about complaints. We will be interested in how you respond to that. We have heard that the rates of restraint and of solitary confinement have increased very considerably. Why is that?

Ray James: Again, part of the explanation here is that the number of providers submitting the data has increased. Part of the reason for the increase is that there has been a 25% increase in the number of providers supplying the data.

Baroness Hamwee: Sorry, can I just pursue that? You do not have complete data. It is getting better, but you do not have data from all providers. How big is the shortfall?

Ray James: There is an issue about the degree of consistency in what is described as restraint and how it is recorded. Work is happening across all the arm's-length bodies to improve the consistency of the application, recording, training and oversight. We are likely as a consequence of that work to continue to see some reported increase in levels of restraint as we get better visibility on where it is happening in overall terms. Through the discussion, training, challenge and scrutiny, we would expect all that to lead to longer-term change. That work is predominantly happening in mental health settings, but of course it is relevant to people with a learning disability and autistic people.

Baroness Hamwee: Are you talking about definitions, or are there categories of statistics that are being reported in some cases and not in others?

Dr Paul Lelliott: This is an issue which the CQC flagged up last year. We published our report on the state of the mental health services after we had inspected every service at least once using our new approach to inspection. At that time, I wrote to NHS England flagging up concerns about how physical restraint is recorded and reported.

The problem we had as a regulator was that we could not rely on the data to compare one provider with another. If we saw high reported use of restraint, we did not know whether that was because a lot of restraint was being used more than in other services, or whether it was just a very good reporter.

We flagged up issues about the definitions used—there needs to be much more specificity about the type and duration of restraint—and the consistency of reporting so that the definitions are applied consistently. Services that are very good reporters of restraint will report any hands-on contact with a patient as restraint. A gentle guiding hand that might direct a confused person away from a trip hazard would be reported as restraint by some services, whereas other services would only report holding someone on the ground.

The other issue we flagged up was the inconsistency of training provided to people who use physical restraint. In response to that concern that we raised, NHS England has been very proactive in addressing those problems. In April 2019, NHS Digital for mental health services, which will include learning disability wards, will bring in the new dataset. That will give us a much better handle on what type of restraint is being used, how much and by whom.

Baroness Hamwee: Have you had an input into what headings are used?

Dr Paul Lelliott: Yes, we have been very closely involved with that work. As Mr James says, that is translating across into learning disability services too.

Baroness Hamwee: Perhaps we should say for the transcript that both our other witnesses nodded. Why is prone restraint being used, to a pretty considerable extent from what we have heard, when the guidelines warn against it? Perhaps I should be asking you.

Ray James: The national guidance is very clear here. There may well be a very small number of circumstances perhaps in which an individual has expressed a preference that if they are distressed to the point of recognising that they may need to be restrained, they would prefer it to be done in that way. That is about the only exception I can think of. The national guidance is really clear. Of all the types of restraint that are reported and recorded, you rightly highlight that one. It is arguably the area of most significant concern, and we would be very keen to see significantly reduced usage.

There are very interesting examples of good practice being applied in some parts of the country already. The Mersey Care NHS Foundation Trust has adopted a programme called No Force First, which has seen very significant reductions in the levels of use of restraint. From memory, it was something like a 47% reduction. There was also a consequent benefit of about a 23% reduction in assaults on members of staff.

As well as improving the consistency of the recording, we are keen to make sure that there is better sharing of the leading practice in this area. Indeed, that particular NHS organisation is currently involved in advising overseas, such is the perceived reputation of the work that it has done.

Baroness Hamwee: Those are still big numbers.

Ray James: Yes.

Q7 **Chair:** Can I pick up on the point you made, Mr James, about people having a note on their file, at their request, that if they need to be restrained they should be put in the face-down prone position? Is that why it is happening, although guidance says this should not be happening: that people are putting in a prior request and approval? How prevalent is that? I do not know what other Committee members think, but I can imagine a lot of people really raising their eyebrows at this. Is it quite normal that you will say, "If I have a crisis, please put me face down on the floor, because

that is how I want it"?

Ray James: Apologies if I have created that impression, and thank you for the opportunity to clarify it. I was trying to describe the very exceptional circumstances that were the only time in which I might consider that it would be felt to be appropriate. It does not justify the numbers, and we would want to see lower numbers.

Chair: Is it appropriate for somebody to give prior approval in advance for something that the guidance says should not happen?

Dr Paul Lelliott: The Mental Health Act code of practice, which is the advisory guidance we pay regard to, talks about not using prone restraint unless there are cogent reasons. Mr James is describing how there are very, very occasionally reasons why it is the preferred option. Someone might, for example, have a problem with their back or some other physical ailment that means holding them on the ground on their back is either more uncomfortable or more dangerous than holding them on their front. That is very unusual, but Mr James was explaining the exceptional circumstances in which it happens.

There is one other circumstance in which prone restraint can occur. If someone is very agitated and staff intervene, sometimes the first point of contact with the floor is face down. The expectation then is that the person should be turned into a safer position for restraint, but good reporters will report that as being prone restraint, even though the person might have been in that position for only a few seconds. That is the other circumstance in which prone restraint is unavoidable and would be reported as prone restraint. I agree with the sentiment that it is a less safe procedure than other forms of restraint and should be avoided at all costs, unless it is absolutely unavoidable.

Chair: Is there going to be publication by NHS Digital from now on of the information that came out by way of a freedom of information request in 2018, which included statistics on restraint and solitary confinement? Is that now going to be published as a matter of course, or will people still have to make freedom of information requests to get it?

Ray James: The intention with the new dataset that Dr Lelliott described is that we will move to a position where there is a mature set of publicly reportable data, which will be open to scrutiny. I am not aware of the precise date for intended publication. I would be happy to let the Committee have it in writing subsequently, if that is helpful.

Chair: You will be asked, anyway, by freedom of information. Whatever state of maturity it has reached, it is going to be in the public domain. Is it not better to just put it in the public domain with a footnote saying, "We are still maturing this"?

Ray James: The sentiment is that through greater consideration, scrutiny and discussion of the data, it will lead to improved practice. I would agree with that sentiment.

Q8 **Jeremy Lefroy:** Good afternoon. Dr Lelliott, you commissioned an

investigation into restraint, seclusion and segregation in ATUs last year, which is reporting, we understand, in March 2020. I wondered why it is going to take so long and what you expect it will say that you do not already know from your normal inspection routine.

Dr Paul Lelliott: Regarding the thematic review, the terms of reference require us to provide an interim report next May and then the final report in March.

I would say two things about the timescale. First, the terms of reference also make it very clear that we should make known any learning and recommendation that comes out sooner. We intend to communicate immediately as soon as we reach conclusions or form recommendations. As we go round the country visiting people who are held in these circumstances, if we have concerns about their welfare we will escalate those concerns immediately. That includes the Care Quality Commission going in and doing an unannounced inspection, if necessary.

The reason why it is going to take the time it is going to take is because the questions we want to address are questions we do not yet have answers to. To get answers to them, we need to do a very thorough piece of work, which will involve investigating most, if not all, people who are held in segregation or long-term seclusion.

To do that work, we have to bring a team of people together. We do not have people who are sitting round waiting to take on these tasks. We have to bring them together. We have to develop our approach. We then have to identify all the people who are held in these circumstances, arrange the visits, and do all this while engaging fully with the very wide community of people who have an interest in this area, which includes people with lived experience and experts by experience. I am sorry to say that we cannot do that thorough piece of work any sooner than the timescales we have given.

The types of questions that we want answers to that we do not have at the moment are about the circumstances in which these people have ended up in the situation they are in. The thematic review will include young people with autism, but it is not just about young people with autism. It is also about people with mental health problems and adults with learning disability. Because this is commissioned under Section 48, it gives us powers that we do not ordinarily have to look at commissioning. We can look at the role of commissioning that might have resulted in this being the endpoint of care or might be contributing to a person remaining in this situation. Those sorts of questions cannot be answered through our normal inspection visits.

When we inspect services, we encounter people in this situation, but when we inspect we are looking at a whole host of other issues. We are not focusing on an in-depth review of all the circumstances surrounding a person's situation.

Q9 **Jeremy Lefroy:** Thank you. That is very helpful. Can I ask colleagues from the NHS what the NHS is doing, during the time of this investigation, to improve conditions for people who are detained? Dr Lelliott has already said that they will produce interim reports or findings if there are things that they feel could change. I just wondered what you are doing within your work.

Ray James: Our primary objective would be to improve the services available in community settings and reduce the likelihood of people needing to be admitted to in-patient settings. We have been strengthening the crisis services, intensive support services and community-based services that can work with people who are at risk of offending or have what is described as a forensic history. We need to be clear about what we do in relation to the oversight of care that we commission.

The long-term plan talks about continuing to work with the CQC and others on reduced use of seclusion and restraint. It also says that the recently introduced NHS Improvement standards for people with a learning disability will be applied to all care that we commission. That will be whether it is in the NHS or the independent sector. There are some clear components of that framework that relate to people's rights as well.

Local areas do this work best where they have the meaningful involvement of experts by experience and family members in checking that quality and in providing feedback and information that can be acted upon. We will continue to stress the importance of care and treatment reviews and care, education and treatment reviews. This was a change in policy that was introduced a couple of years ago.

As I said earlier, four out of five of those are now resulting in a decision not to admit but to alternative services being put in place first. Our focus will continue to be on what every local area needs to do with and for an individual and their family to reduce the risk of admission.

Jeremy Lefroy: Can I move on to the CQC report on St Andrew's Hospital? I understand that, as of today, the report has still not been published. Is that the case?

Dr Paul Lelliott: That is correct.

Jeremy Lefroy: Can I ask why it has not? We understand that it was expected in December.

Dr Paul Lelliott: The inspection you refer to was undertaken in November and we have only recently finished gathering the evidence that we need. I was particularly interested to make sure we had talked to families and carers particularly of young people who are held in segregation. The evidence collection is now complete. After we quality assure the report, it needs to go to the provider, which has a period of a couple of weeks to comment on the factual accuracy of the report, and we will then publish it.

This is not the first or only inspection we have done of these services. I have looked at the records, and we have undertaken nine inspections of St Andrew's over the last two years, and in the last year this is the third inspection that has involved the children's services. We have had pretty close contact with St Andrew's during the last year.

Jeremy Lefroy: What has been the result of those inspections and reports?

Dr Paul Lelliott: Focusing on the area of interest for this Committee, the nine inspections included other services provided by St Andrew's, not just the children's services or learning disability services. In a number of those services in 2017, we identified concerns with seclusion and segregation, about the procedural management of those interventions.

In October 2017, after we had raised those concerns, one of our Mental Health Act reviewers visited the young persons' ward and, again, focused on segregation and exclusion. Their conclusion was that at that time the expected care plans and education programmes were in place. Then, in April 2018, we reviewed care records in the children's mental health services. Again, at that point, we concluded that there were no grounds for taking regulatory action. That was the last time we visited. This current inspection, as I say, will be out in the next few weeks.

Q10 **Ms Karen Buck:** You will probably be aware of some of the witnesses we have had in the course of the inquiry. Listening to the evidence from some of the parents we have spoken to, we have heard concerns expressed that, when they have raised complaints, when they have raised concerns about their children, there have been consequences. They feel that action has been taken by the units that has been detrimental to them and their relationship with their children.

What is your view on that, particularly from the NHS, and have you undertaken any inquiry into the extent to which those concerns of the parents are justified?

Ray James: As a result, in part, of some discussions I had with parents that were facilitated by the Challenging Behaviour Foundation and Mencap a couple of years ago, we have worked to introduce a new approach to complaints handling called "ask, listen, do". It has been led by parents and shaped with them to set out the way in which we would expect things to happen. Indeed, Baroness Hollins was kind enough to host a launch of that in this House for us.

We have done that work to be clear that we think there is very real benefit in making the effort to ask in the first place, not waiting and relying on complaints coming forward. When messages are received, they should genuinely be listened to and lead to some action. Dr Lelliott may have more to say in relation to what the CQC does when it looks at complaints functions et cetera, and their use by registered providers. The

NHS, alongside any other commissioners, will have a role to play in the resolution of those. We would not expect providers to take that stance in relation to individual families. If we get details of anything, we will act robustly.

Ms Karen Buck: Do you know how many times you have acted in response to these? Is that routinely monitored?

Ray James: As I said earlier, I am not personally directly involved in individual cases. I would be happy to talk to my colleagues who work on the prescribed specialist commissioning teams to get the detail of that. We monitor complaints information, but on the specific element of whether parents have said that that has led to adverse reactions to them, I would need to go back and inquire about that. We would encourage exactly the opposite: we would encourage providers to actively ask for feedback.

Ms Karen Buck: I am sure you would, and there will be separate questions on the actual complaints procedure, but it would be very helpful if you could come back to us with an indication as to how these concerns about possible reprisals—I hesitate to use that word, but we know what we mean by it in this context—are brought to the attention of NHS England and what happens.

Very specifically, you may or may not be able to answer this question on the use of injunctions, which has been raised with us. Are you able to say whether you monitor the extent of the use of injunctions where complaints and concerns are raised?

Ray James: I am not aware of NHS England ever using an injunction in that way. I made a point of asking the legal team before the proceedings, and they are not aware of NHS England ever doing so either. It may well have been other bodies that were referred to in the evidence that you heard.

We would have a look at any specifics, but I am not aware of NHS England ever doing something. It is not our policy to do so. It is quite the opposite. As I said earlier, we would always encourage much more constructive dialogue, seeking to use the fact that parents are often the people who know their family member best. They should play a central role in helping to shape what is needed and what the appropriate care and support would be.

Ms Karen Buck: In Bethany's case, one issue that was brought up to us was the use of data protection and concerns about the privacy of the patient sometimes getting in the way of the relationship with the parents. There is a balance to be struck and the patient will have legitimate needs for their privacy to be safeguarded in some circumstances, but where permission is given, or has been assumed, that should not get in the way.

What is your view on the extent to which data protection and privacy were used as a justification for units not relating to parents in the way that they should?

Ray James: I have two thoughts on that, and I have to be careful that I do not present this in the way I did earlier. Primarily, I do not see that that should be the case in those circumstances. There might be a few exceptions where an individual has capacity and has expressed a desire for it not to be communicated or shared in that way with certain people, but that is a very small number of cases rather than the norm.
We would always encourage the discussion to take place in a meaningful and open way with the best interests of the individual receiving treatment at its heart.

Ms Karen Buck: I am hearing your words of reassurance, but presumably you are aware that in the NHS, or in the services which the NHS will sometimes contract, reasons and justifications will be given that are not necessarily in accordance with policy or, indeed, even the law.

Ray James: Where specific issues of that nature are brought to our attention, I would hope that we would always work to resolve them. Where we are commissioning the care or treatment of an individual young person, there is a case manager assigned to that, who would be involved more directly in those circumstances. I am probably more familiar with the difficulty about commenting publicly. I am not sure if that is what your question was about. You were talking about the sharing of information with family members and others in that way.

Ms Karen Buck: They are two separate issues.

Ray James: Yes. On occasion, other public bodies may have statutory duties or powers in relation to the individual concerned, but, again, none of that should be a barrier to people coming together in a way that consistently focuses on what is in the best interests of the individual.

Ms Karen Buck: Are you clear, as NHS England, in getting that advice out to all the branches of the service that may be involved here? Can more be done to improve that?

Ray James: We are clear about our contractual relationships and what we express there. If anything is brought to our attention through the case managers, we expect in local areas that they will work to resolve it.

Ms Karen Buck: Can I ask the Care Quality Commission whether you have a view on this, and indeed whether family members sometimes come directly to you to ask for CQC involvement in this?

Dr Paul Lelliott: Yes, we get approached directly by family members. Sometimes the family members come through national organisations that represent their interests—bodies such as the Challenging Behaviour Foundation. We often get feedback then. We would respond to each contact on its merits. We would certainly expect the local inspector to follow it up. Invariably, that would involve a conversation with the family member to find out what the issue was. I quite often meet family members of people who have concerns.

Ms Karen Buck: If you are tracking this, is it on the increase? Do you get a sense that it is?

Dr Paul Lelliott: I do not. I could not say that it is on the increase, but I think there is a long-standing problem of family and carers being excluded from care decisions. I would not take my evidence from this very specific area, but the Mental Health Act review report that was published very recently acknowledged that family members are often excluded from being given appropriate information and from involvement in decisions. Quite often, the grounds for excluding them are on the basis of confidentiality.

There is a problem in this area. I think the Royal College of Psychiatrists has issued guidance about the appropriate way to involve family and carers both in receiving information and in decision-making about people's care. It is an issue. There are many clinicians around the country who do not have it right, but I am drawing now on my past clinical experience, because I was a consultant psychiatrist.

Ray James: It was the level of concern from family members that led us to work with them to produce the new guidance. Clearly, that is also suggestive of a significant level of concern.

Ms Karen Buck: As a last question, what is the procedure for achieving the same ends where we are dealing with young people who perhaps do not have involved family members?

Ray James: There will be a couple of potential arrangements there. We would expect our own case managers who are overseeing the case to do that, but there also ought to be arrangements for advocacy in respect of the individuals concerned. Where there are statutory provisions associated with their mental health, similarly there will be clear expectations in the code of practice.

Q11 **Chair:** Has there been any consideration of requiring an assessment of the level of positive approval by parents or family members in relation to the appropriateness of the placement or the care and treatment of the young person in the placement? After all, the parents are, albeit not necessarily mental health care professionals, the people who care most about these children and adolescents, who have the long-term relationship with them. If they are expressing concern, they are like the canary in the mine, are they not? That should really make people concerned.

I do not know whether you are aware that universities and higher education institutions have a thing called the National Student Survey. Every student can—they can decide not to—fill out a form to contribute to the National Student Survey for their own institution. Each student has to rate their higher education organisation as to whether they are being properly supervised, whether there is proper feedback, whether it is all being properly arranged.

The higher education institutions are rated every year according to these categories. Their knees tremble at the thought of whether

their students, who of course they cannot control, are anonymously going to give them a good bill of health according to these criteria, which are public policy criteria. It makes institutions really think about what they are delivering for students.

Have you thought about whether, in every case where a child or young person is detained in one of these institutions, there should be a requirement for the parents to sign, anonymously, according to various criteria: "Do you think this was the appropriate placement?" "Is this person in the right place—yes or no?" "Is the treatment and care of this person in this place good—yes or no?" "Have you ever had cause to complain? If you have, was your complaint listened to when you raised a concern?"

Why do you not put it into their hands, instead of or in addition to yours? You are the macro inspector and you have teams of inspectors going in professionally, but you must wonder sometimes whether you are missing something that is going on that parents know about. If parents do not know about it, it is probably not going on.

Have you thought about the equivalent for these institutions to what is done with the National Student Survey? If it can be done at the scale that there is with students, which is a much bigger scale, surely you could do it. Then you would get such a good picture about whether a complaint is an outlier and an exception, or whether there is something going on.

At the end of the day, it is very subjective, is it not? If the parents are not happy, even if their unhappiness is not objective, their subjective unhappiness as the people who care most about the child should surely matter to us all.

Dr Paul Lelliott: Yes. The first remark to make is that the Care Quality Commission has something a bit like that. Every year, there is a survey of people using community mental health services. We get tens of thousands of responses. As well as publishing nationally what people's experiences are of these services, we break them down by NHS Trust. That information is fed back to the trust. If a trust is performing particularly badly, that is picked up on. So we have something like that.

Chair: That is for the community.

Dr Paul Lelliott: That is right.

Chair: I mean by institution.

Dr Paul Lelliott: It is by institution in the sense that the results are broken down for each of the 54 mental health trusts in the country.

Chair: Yes, but the trust is not an institution as the parent would know it. You get the point.

Dr Paul Lelliott: Yes. I would expect that, when we inspect, every effort is made to talk to the families.

I take the point that their perspective on care is very valuable. Although they are not independent, because they have a huge interest in the young person, they have a fresh pair of eyes on the quality of care being provided in that institution. The feedback they give is absolutely vital. What you are suggesting is a very interesting idea. I am not sure how to put this, but if we had the funding it is something we would think about. The point underlying your suggestion is that families have vital information that we would hugely benefit from in our regulation and inspection of services. This is totally valid. I accept that 100%.

Ray James: I have a couple of thoughts. First, NHS England is fortunate enough to work with two colleagues who we employ directly as parent advisers, as a result of their lived experience as parents. They bring their expertise and their connections with other parents to inform our work and approaches. We would expect the contribution of parents to be central to the care, education and treatment reviews that should always happen before a young person is admitted, so that they are involved in helping to look at the feasibility of every possible option.

Chair: But do you record the outcome after? You say that you expect them to be included, but once the decision is taken do you record whether the parent thinks it is the right or wrong decision as far as they are concerned? It is about the placement and the care within the placement.

Ray James: As I mentioned earlier, 79% of those, four out of five, lead to a decision not to admit at the moment. We have not done the specific work that you describe in relation to the parents' view on the choice of placement, but they should always be involved in that.

I want to draw attention to another issue, particularly for people with a learning disability and autistic people. There is an approach to checking the quality of a service provider that directly involves other people with lived experience. It is called quality checking, and you can often have much more meaningful feedback and conversations through this—for example, another person with a learning disability who has been trained goes into the facility, and will talk to people to get their views and feed them back.

That is not the sort of systematic rating that you talk about, and it is interesting that the CQC may consider something of that nature. I have always felt that the more public and transparent you can make people's experience of a service provider, the more likely that service provider is to take action to improve their experience.

Chair: The body that does it in higher education is not the OFS, the regulator; it is not the CQC. It is the institutions. They have the obligation to do it. There is something of value in the fact that it is routine. It is not just based on whether you are getting a load of inspections. Bearing in mind that we are talking here about the particular dangers and vulnerabilities in a residential setting, when it is in-patient, when it is detention, it is a small number, but the issue of what is going on in that institution is crucial.

Why do you not want to have the security of knowing that every year, in respect of every in-patient, the family are being asked to positively certify? The other things that you have mentioned are all very encouraging, but it is not the same. Why do you not pilot it, for example?

Ray James: I have two thoughts. To the point you made at the beginning about it being the responsibility of the university, the provider, the ideal would always be to commission services from organisations that have a robust and sincere approach to quality, where they involve a degree of independence in their approach to quality, in the way you describe there. Our efforts tend to focus on the individual level. I am happy to undertake to come back on what we might be able to do more systematically, in aggregate, to share the information and feedback we receive from family members.

Chair: You have lost me there. I am afraid I do not understand your response. It is too complicated. Do you think it is a good idea that when there is a residential placement the parents should positively certify whether they think it is the right placement? Should you know that in respect of every placement? Should you know every year for every parent that they think it is the right placement on a continuing basis, and that the care is good?

Ray James: It has to be helpful if we can seek feedback more consistently from parents about their experience of the placement. That may include the decision at the outset, but it would also be useful to get consistent feedback about their experience during it.

Chair: We need something routine, rather than consistent. It has to be absolutely routine and hardwired in the system, has it not? Otherwise you are going to get gaps.

Anyway, it is just a thought. I will draft the form for you if you want, because we have heard from the parents about their concerns. The form would be very easy to draft, and they are all online, so it would not cost much.

Ray James: We would probably ask parents to help us to design that in the way they thought was best.

As to the principle behind what you were suggesting, when I say "consistent", I do not mean anything that is in any way different from routine. Apologies.

Q12 **Lord Woolf:** I have a very clear picture. You recognise that having families' views in cases where there is relevant family is very important. You also told us about the steps you are taking to find out families' views.

Finally, on this matter, could you give us your impression as to whether, at this time, the families have got to a position where they appreciate what I have just said is your attitude? In other words, do they recognise that you are looking for their views and you regard their views as being important?

Ray James: We have had very helpful involvement with individual family members and organisations that represent them or that they are a part of, and we value their input and will continue to do so. I think families would recognise that some difference has been made, but they are understandably impatient that that difference is made consistently in every part of the country, for every individual and their family.

Lord Woolf: Because of that, it is an area where you really have to concentrate. Would you agree?

Ray James: In part, that is why we have chosen to employ directly two family members: so that their insight and their expertise can help us sustain that focus.

Lord Woolf: Is two enough to employ?

Ray James: We employ two in the central team nationally. We are really keen to extend the employment of people with a learning disability and autistic people, as well as family members, in every area of the NHS. Indeed, we would commend it more widely across public service. The long-term plan includes some commitments for our part in that respect.

Lord Woolf: Thank you very much for that. I wonder if Dr O'Hara has any comment to make on this area. You have been rather left out of the direct answers.

Dr Jean O'Hara: Yes, thank you very much. I would like to mention my colleague in NHS England who is the lead psychiatric clinician. He has been working very hard with an organisation called Bringing Us Together. It is a family organisation, working in partnership with psychiatrists so that we go forward together. That is a very big step, because I think many psychiatrists, when they see somebody in their clinics or whatever, do not appreciate the whole history that the family has gone through before they come through the door. That sort of insight and real partnership with families is really important. That is a very positive step.

Lord Woolf: It sounds as if it would be a very good idea to get the psychiatrists' assistance as well on this particular aspect.

Dr Jean O'Hara: Yes.

Chair: Thank you very much indeed for coming to give evidence today. It has been extremely helpful. Thank you for the work you do as well.