



HOUSES OF PARLIAMENT

Joint Committee on Human Rights

Oral evidence: [Detention of children and young people with learning disabilities and/or autism](#),

HC 1861

Wednesday 3 April 2019

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

Questions 20–29

Witness[es]: **Caroline Dinenage MP**, Minister of State for Care, Department of Health and Social Care; **Jonathan Marron**, Director General, Community and Social Care, Department of Health and Social Care

Q20 **Chair:** Thank you very much indeed. We are very grateful to you, Caroline Dinenage, for coming to give evidence to us in your role as Minister with responsibility for care in the Department of Health and Social Care. We are also very grateful to you, Jonathan Marron, for coming along as the director general for community and social care in the Department of Health and Social Care. As you know, we are the Joint Committee on Human Rights, which means we are half Members of the House of Lords and half Members of the House of Commons. We are concerned in relation to human rights. In this inquiry, on the detention of children and young people with learning disabilities and/or autism, the human rights we are concerned with are the deprivation of liberty, the question of the right to family life and the right not to be subjected to inhuman or degrading treatment. That is our locus, our area of concern, when we look at these issues.

Can I start by asking the first question? There has been quite a lot of agreement among families, professionals and commissioners that, when young people are detained, many of them are in a place which they do not need to be in, which they should not be in and which, ultimately, is even making them worse. Do you accept that to be the situation? If so, why is it the situation that some of these young people really ought not to

be in the placements they are in? Is one of the factors the inadequacy and lack of support for families caring for their children at home, which leads to a crisis, which leads to the young person being detained and spiralling down? Can we start with that point about the appropriateness or otherwise of the detention?

Caroline Dineneage: That is a long question. I apologise; it is going to be quite a long answer, and then Jonathan will step in and correct me. First, thank you so much for inviting us. This is such an important inquiry and one that we are also very deeply concerned about in the Department of Health. We have done an enormous amount of work on transforming care and building the right support in the community, so this is an incredibly welcome addition to that work.

Children and young people find themselves in what you might call tier 4 in-patient settings for a number of reasons. Sometimes it is because there is an unavoidable crisis point. It might be something to do with the family, and it might be something that has crept up on them at the last minute. All too often, what you have heard is right: young people end up in an in-patient setting as a result of a number of failed opportunities to intervene earlier, provide the right support and maybe diagnose them from an early stage.

We find there are an increasing number of girls in in-patient settings with autism, but they did not come into an in-patient setting with that autism diagnosis; they came in with a mental health diagnosis, which is usually something around self-harming or an eating disorder. Only when they are in the in-patient setting is the autism diagnosed. It is about how we can get that diagnosis much earlier on in their lives, so they and their families can get the right support.

Sometimes, as you say, it is because the families do not have the adequate support that they need in the community and, particularly for boys with learning disabilities, as they get older. I am the mother of a teenage boy. They get big, hormones kick in and sometimes a family can reach crisis point. If there is not the relevant support, sometimes that can happen.

Fundamentally, it is the case that, often for very good reasons, people are admitted to these in-patient settings for a very short time for a therapeutic intervention, but the very nature of being there can cause distress and can accelerate or aggravate conditions that people already have. We need to look very carefully at whether these are ever really the right settings for people, and look at the minimum possible intervention and maximum possible support in the community. If people need to go into an in-patient setting, we need to make sure it is for the shortest possible time with a very clear route to their pathway out, knowing what that care in the community and support in the community would look like. A lot of what we have been doing—I am sure we will come on to discuss it—in things such as Transforming Care, building the right support and

working on mental health support and provision in education, goes to support those aspirations. Have I forgotten anything?

Jonathan Marron: No, that is a very good answer.

Chair: Thank you very much indeed. Yesterday, I was at Tuke School, a special school in my constituency, talking to parents with autistic children. The week before, I was at Cherry Garden School. They are all having their packages of care cut from 24 hours to 16 hours. As their children grow, as you say, they often can become more challenging. Thank you very much for that very full answer, which really cues in the next question from Scott.

Q21 **Scott Mann:** The Transforming Care programme aimed to move between 35% and 50% of people with learning difficulties and autism out of hospital into the community by the end of March 2019, but it failed. In fact, the numbers of children detained have more than doubled. In January this year, the NHS long-term plan set a revised target to reduce those numbers. What needs to change to make sure those targets are achieved?

Caroline Dinanage: Thank you, Scott. That is a really important question. The key aim of Transforming Care is to develop robust and appropriate community settings so we can close in-patient facilities for people with a learning disability and/or autism who display challenging behaviour, including those with a mental health condition. The goal, as you say, Scott, was to get that number down by between 35% and 50% by 2019. It does not take a genius to figure out that it has not been achieved. We have reduced the number nationally by just over 20%.

That does not mean that the programme is without successes. We have had an enormous amount of learning along the way. We found that there are very significant geographical variations. In some parts of the country we have hit and exceeded the 35%, for example. Around a quarter of the Transforming Care partnership areas have reduced it to the appropriate levels. For example, Nottinghamshire and north and central London have reduced their in-patient numbers by at least 35%. Suffolk, Worcestershire and London south-west have not only reduced their in-patient numbers but reduced in-patient capacity, which is what we wanted to see. Of course, others have done less well, which makes the figures look worse across the country.

Of the care, education and treatment reviews, which we established as a vehicle for trying to prevent admission in the first place, where they have been carried out, 85% led to a decision not to admit. They have been very successful at involving families and diverting young people from an in-patient setting.

It is important to point out that we now have a much better understanding of where the challenges lie. We had not really included thoughts about children and young people as much as we should have done when we first set out on this path. We had not fully captured the

impact of population growth. We had not accounted for this big increase in autistic people in the figures. These are things we have all recognised and addressed as we move forward, and the NHS long-term plan is committed to this target, as you know.

Scott Mann: I have a quick follow-up, if I may. I went to visit an organisation in an old social care building that specifically does this. It provides independent living for people who have learning difficulties or autism. Should it be a legal right for people to have the ability to ask for that?

Caroline Dinanage: Do you mean living independently?

Scott Mann: Yes.

Caroline Dinanage: Yes. One of the key parts of the Care Act is the ability for people to have that aspiration to be supported to live independently and for the health and care system to enable them to do that.

Jonathan Marron: On Transforming Care, a 20% reduction is nothing like what we hoped to achieve, 35%. We have committed to hit the 35% by the end of the current year that has just started, and the 50% by the end of 2024. We have not given up on delivering the original aspiration. In doing what we have done, we have managed to discharge over 6,000 people from these institutions. It is a really significant programme of successful discharge. We have decommissioned 476 beds. Part of our challenge is that we have kept on admitting more people. As we have gone through the programme, we have understood much better that this is a challenge of not just discharging people who have got stuck, but stopping the flow of people whose placements in their community or, indeed, with their families, as you pointed out earlier, have broken down and who have ended up in hospital. How do we make sure we then discharge those?

The other thing that we are significantly investigating is the scaffolding of NHS community services that are needed to allow independent placements to work. How do we make sure we have crisis services from the NHS, forensic services and intensive support that allow us to very safely hold people in the community in the sort of settings that we would all, and certainly if there are relatives, like people with learning disabilities or autism to live in? There is an ongoing learning for the NHS about what we need to run a community service with far fewer beds.

As the Minister points out, the variation across the country has been enormous on beds. There was a six-fold variation when we started, down to three and a quarter now. We are making progress in getting to a much more standardised model of care across the country, but we have a long way to go for this year and the next two.

Scott Mann: One of the things that they utilise within this setting is technology to help facilitate independent living. In terms of your ask within the NHS budget, are you looking to specifically target independent living through the use of technology, so people know they have opened

their fridges or switched their kettles on so many times in a day, and so they are up and about?

Caroline Dinenage: Yes. Our boss, the Secretary of State for Health, has always set out three priorities for his time as Secretary of State. One of them is workforce, one is prevention but the third is technology and how much it can be used. Sometimes, when I say that, people in the room roll their eyeballs, thinking that we are going to use technology to replace humans and experts, but it is about how technology can be used alongside skilled professionals to do the things you have mentioned.

Jonathan Marron: The technological opportunities that are open now are very exciting, not least the kind of technology that is available as a consumer product and is easy to use. You can think of Amazon Alexa and touchscreen-based things, which are so much simpler for people to live with, compared to earlier attempts at assistive technology, which are perhaps slightly more difficult and more expensive. We are on the cusp of being able to do things. In this space, in dementia care and in a lot of care for older people, technology will be a big part of how we do this.

Chair: Can I follow up on the geographical variations you mentioned, with some areas doing much better than others? Have you looked at and identified whether there is any correlation between local authorities having enough resources to support people to avoid crises when they are in the community, so they do not end up having a residential placement because there is not enough NHS community support or social services community support? I can think of many of the parents I met in Tuke School, who are always just a whisker away from a crisis anyway, because of the level of support they have to give children with a high level of need. Is there a correlation between failing to meet the targets for reducing residential placements and the overstretched resources in an area's council?

Caroline Dinenage: We are doing more work on this. We have a big piece of work on our Transforming Care and building the right support agenda. We are looking much more forensically at different local areas and seeing what other challenges they may have, even to the extent of how successful they are as local authorities. The other important thing is, where there are pockets of really good practice, looking at what they have done differently that we could recommend to other areas to build on and use. It is a combination of both things: looking at where local authorities need that more fundamental support, and looking at where really great practice is happening and how it can be replicated.

Baroness Hamwee: When you were talking about the interviews on admission, you said "where they have been carried out". Can you help the Committee as to the proportions that actually happen, how successful they are and what is going to happen after March? Well, we are after March now. I think the Transforming Care programme provided for reviews every six months of numbers and quality.

Caroline Dinenage: The figures that I have show that, in 2018-19, up to the end of February, 530 pre-admission CETRAs were carried out, 85% of which led to a decision not to admit the young person. The proportion of in-patients who are recorded as not having had one is now below 6%. This includes people who have refused one. We are finding that compliance is improving as well, both before and immediately after admission, and for repeats for in-patients. Once again, we have a geographical variation in performance here.

Q22 **Baroness Prosser:** Can I move on to the question of restraint and solitary confinement, particularly in assessment and treatment units? We understand from the figures that this practice has been increasing, but I think there is some question as to whether those figures are correct. Hopefully you will be able to fill us in on some of that. When you are explaining all this to us, can you tell us whether some of this may be to do with having insufficiently trained staff or a high turnover of staff in these units, where relationships must be very important to keep things on an even keel?

Caroline Dinenage: I will kick off and let Jonathan fill in some of the details. We have to be very careful with the data here. It is to our shame that our data is not more robust, but it simply is not robust enough to make accurate comparisons year on year. It will be from hereon in. We are a lot more careful about data now.

Baroness Prosser: Is it possible to explain that briefly, or is it a long story, so we understand what the issue is?

Jonathan Marron: Before 2015, we did not collect this data at all. This is new data collection, a mental health services dataset. Essentially, we published it as soon as we started collecting it as an experimental statistic, because it is better to be transparent and open about the data we have than to hold on to it to the point that we think it is robust and reliable to compare year on year. That is a deliberate choice to make the data available and use it, but it is clearly badged as experimental.

We are much more confident in the 2017-18 data than we are in the 2015-16 data. If you look at individual data, what it shows you in the year is useful. Using it to show growth between 2015-16 and 2017-18 is really difficult, not least because, I believe, in the first collection of 2015-16 only 50 or so providers provided data. There were more than 70 providers in the later years. With more providers giving data and higher numbers, it is quite hard to see what is real growth and what is simply better capturing of what is going on.

As the Minister says, we are much more confident now. If you are looking into next year's data, you can start to draw some distinctions. That said, the data on the individual methods of restraint gives us interesting material. I am sure you are going to ask us about the use of prone

restraint, where there are high levels and certainly not the levels we would be comfortable with.

Baroness Prosser: Perhaps we can hear about that in the response as to what you think it is down to.

Caroline Dinanage: What is it down to? This is why we have asked the CQC to do a thematic review on the use of restraint, segregation and seclusion, because it is obviously very worrying. We are very clear that there should never be targets for this. It should be the very minimum necessary to protect the individuals themselves, but also to protect staff. The CQC is looking at this. We need to look very carefully to ensure the workforce has sufficient training. We need to ensure we have sufficient numbers in the workforce. There is a whole range of workforce activities going on in this direction. You can completely understand, if a young person ends up a setting like this and is then restrained, secluded or segregated from others, how that would magnify any existing problems.

Baroness Prosser: It would make matters go from bad to worse, probably.

Caroline Dinanage: That is exactly right. We have heard of some horrifying crises in the press. None of us would ever want that for our children, so we have to do everything we can do address it.

Baroness Prosser: At the moment, you do not have the evidence to say whether this is due to insufficient training. You must have evidence on staff turnover, I imagine.

Caroline Dinanage: Staff turnover is very difficult, because they are not all NHS employees. There are some independent providers and there is some NHS provision. We will get a lot more information out of the CQC thematic review on this.

Baroness Prosser: When are you expecting that?

Caroline Dinanage: When are we expecting that?

Jonathan Marron: The first phase will complete in May this year, looking at learning disability and patients with autism in in-patient settings, with a broader look at residential care and mental health by the end of the year. Can I add a couple of things on the position on restraint? We have pretty solid guidance, which I have brought with me. *Positive and Proactive Care: Reducing the Need for Restrictive Interventions* was published in 2014. It is clear that we should use the least restraint possible. Indeed, behavioural methods to reduce aggravation and try to calm people down are much better, but, if we are going to use restraint, it should be the least restraining method. Prone restraint we do not think should be used deliberately.

Chair: Remind everybody what prone restraint is, because people listening may not know.

Jonathan Marron: It means face down. Normally people think of being face down on the floor, but it could be face down on a table or anything else. It is a concern because it can affect the airways. We would rather people did not use it. The guidance is clear that it is not always possible

to avoid it. I am no expert in how you do restraint, but you can imagine, if you are physically restraining somebody, it is not always possible to do it in a totally controlled way, in which case we may end up with prone restraint. Again, the guidance is clear that staff should try to change their hold and reduce the time spent doing it. That is the first part.

The guidance was aimed at all patients but there have been some concerns that, for under-18s, we should be thinking about specific guidance. We have worked with the Council for Disabled Children to produce some specific guidance for use of restraint in under-18s. We have been working on refining that with stakeholders after a consultation period. That should be published shortly. It is extra guidance, to make sure we have got the nuance for children right.

In terms of staffing and training, NICE has, in its standards for children and young people's mental health services, requirements for staff to be trained in the use of restraint. We funded the British Institute of Learning Disabilities to establish a restraint reduction network of providers and service users that are interested in this. It has also produced training standards to say, "This is the right way to train people". We have worked pretty hard on the standards, guidance and training practices there. The CQC review will give us a really in-depth look at what is actually happening in our services. That will help us think about what other action, if any, is needed.

Chair: We are talking here about a young person with one or more people holding them face down on the floor or possibly over a table. Considering that, as a snapshot, about 260 young people are in these units at any one time, the figures show that, for 2017, there were 3,170 recorded episodes of prone restraint. That suggests a real prevalence for something that should not be happening at all. How concerned are you that this is being quite routinely used?

I have another question. Presumably, you monitor issues such as staff turnover even if it is a private provider, because high turnover of staff can indicate problems, can it not? Is that something you keep your eye on even if you are not the direct employer?

Caroline Dinenage: The CQC inspects all providers. Staff turnover would be an indicator of something more concerning about that setting, yes.

Jonathan Marron: There are a couple of things. We are concerned by the numbers. This is not the level of prone restraint that we expected to see. The Secretary of State has been very clear that he is concerned and has asked the CQC to do an in-depth thematic review. We have talked a little about the limitation of the data already, so we want more evidence.

Chair: He is at the point of asking, "Why is this happening?", rather than saying, "You have to stop it". What is the message coming from on high: "Let us understand why you are holding these children down"?

Jonathan Marron: It is the other way round. We have been clear in our guidance since 2014 that we do not think this should happen. It seems to

represent 14% of the use of physical restraint in the last year and about 20% in previous years. We are concerned about that level.

Chair: Have you issued a follow-up to that guidance document you showed us to say, "We are alarmed by the figures. You should be doing a lot less of this. If you are doing it at all, will you please stop doing it"? Is that the message that is going out?

Jonathan Marron: The CQC is doing its review, which will give us much better information and ability to make decisions on what is happening. We have an improvement programme across our arm's-length bodies looking at three sets of things: the recording, to make sure we are accurately recording restraints so these numbers can be reliable; the training requirements so we have our staff properly trained; and an improvement programme with NHS England looking at the use of restraint and our people. We are responding to what are concerning numbers. As the CQC completes its review in May and provides us with this information, we will consider what further action may be needed.

Caroline Dinanage: You are right, though. It is a huge concern, which is why the Secretary of State has taken this action of an in-depth thematic review, because it is extremely distressing.

Q23 **Fiona Bruce:** I would like to talk a little more about involving families in decisions. You have told us, Minister, that you have had some success in involving families to divert young people away from in-patient settings. We have had information from families that they sometimes feel powerless because they are not involved in decisions affecting their children, even though they are the people who love them most and are likely to be involved with them for all their lives. We wondered if you could tell us how that can be resolved. Some of these parents are saying they even feel fearful to complain, for fear that it might make matters worse for their children or young people. What is your view on whether there should be a legal presumption that parents should be closely involved in all decisions or matters relating to their child or young person?

Caroline Dinanage: It is an extremely important point that you make, Fiona. This morning I was chairing our autism group, which is an annual group that looks at how we define our autism strategy and improve it. One clear message that comes out is how people sometimes need their parents to fight for them when it comes to community services. You can only imagine how distressing it is as a parent to feel that that ability to fight for your child has somehow been removed from you, so we want to do everything we can.

One of the key learning disability standards for all trusts is to ensure that people who have learning disabilities, autism, or both, and their families and/or carers, are empowered to be partners in the care they receive. It is really, really important.

We have to have a balance. It is difficult to give carte blanche. You have to do this by law, because there are cases where the young people, so the older people we are talking about, are what is called Gillick competent. Young people with learning disabilities or autism have sat in my office in the department saying, "We want to be able to make decisions over our own lives". One particular gentleman was very clear to me that his parents would wrap him in cotton wool. He had a partner and a home, and his mum and dad would have wrapped him in cotton wool and not enabled him to do any of that. We have to be very careful about giving individuals the opportunity to make decisions about their lives.

But we are very clear that this is part of the learning disability improvement standard. Involving the family early on is enshrined in the arrangements for special educational needs. The family and the young person themselves must absolutely be at the centre of these care, education and treatment reviews. We are seeing three out of four of them result in an outcome other than an admission, which shows the value of having the families involved there.

Fiona Bruce: On the issue of the legal presumption, from what you are saying, you feel it is probably not helpful.

Caroline Dinenage: Yes. We have to be careful. We have looked at it. You will be aware that I just put forward the changes to the Mental Capacity Act concerning deprivation of liberty safeguards, or liberty protection safeguards as they are now. We had to consider that very carefully, because we have now extended those to 16 and 17 year-olds. We absolutely want parents to be involved, but we have to be very wary of making a carte blanche legal decision that may not be right for absolutely everybody.

Jonathan Marron: In the long-term plan, the NHS has committed to ensuring that everybody has a key worker, so somebody is provided by the commissioner who understands your case and can talk to the family. Particularly given what you said about people who are worried about raising concerns because it might have an effect on their provider, a key worker who is not part of that could really help with those situations. That might help.

Caroline Dinenage: We have pilots that are doing that already and are seeing really great results.

Fiona Bruce: May I ask one slightly tangential supplementary? You used the term "autism", but I wonder whether it covers a multitude of issues that may present, such as foetal alcohol syndrome. There are quite a lot of diagnoses of autism which evidence to our all-party group on that subject indicates may be foetal alcohol syndrome.

Caroline Dinenage: The calculation at the moment is that, of the roughly 250 young people in an in-patient setting, approximately 70% are autistic. We reckon about 70% of those also have mental health issues, and very many of them have other health or complex care needs. Epilepsy is also a very common co-condition with autism.

Fiona Bruce: They would all be individually assessed and then an approach taken that is as appropriate as possible for their needs.

Caroline Dinenage: That is right.

Chair: To follow up the point Fiona has made, some of the families watching this evidence session might be thinking that it is not so much a question of involving the families, but a question of not shutting them out. We have heard evidence that families are shut out, and are desperately keen to be involved but are excluded on a routine basis. It is very wearing and draining for them to keep trying to get into the decision-making process.

Could one of the things you could be doing be providing support for the organisations that have sprung up which support parents? If you have a concern about your child, it feels a very lonely place. It is very important for parents who have an understanding of the system because they have children in a similar situation to support each other. Does the department fund those organisations, despite the fact that they are likely to feel a bit like a challenge to the system, because they support the parents, who are the people who know and love the children most, as Fiona said?

Caroline Dinenage: We are never afraid of a challenge. We have a lot of what we might call critical friends within the Department of Health and Social Care. We very much embrace that, because you can only improve when people tell you straight up where the issues are. I do not know whether we fund any of those, but it is an excellent suggestion. If we do not, we should definitely consider it.

Jonathan Marron: We have just launched a call for evidence for the refresh of the autism strategy. We were talking about that with the group the Minister talked about earlier. This issue of how we support families was clearly on the agenda, so that is one of the things we will look at as we do that work.

Caroline Dinenage: It is very important. We get a very clear message from families of autistic young people or people with learning disabilities. As I said to Fiona earlier, there is often the feeling that parents and families have had to battle for what their kids need. That should not have to be the case. Then you worry terribly about the young people who do not have individuals to fight that battle for them. This is why we have to be very mindful of making sure that that support is there, and particularly the early diagnosis, so the support can fall in behind it.

Q24 **Lord Woolf:** I should disclose that I have a member of my family who is autistic. I am going to ask you about the use of injunctions, but before I come to that, based on the general evidence you have given, is there enough emphasis on training of staff? It is very, very difficult to know what is required, and I wonder what you feel about the standard of training.

Caroline Dinenage: I am very keen that all health and care staff have some level of learning disability and autism training. We have a

consultation on this very issue happening right now. When I say “all health and care staff”, I do not mean solely medical professionals, because we all know that a negative interaction with somebody such as a GP receptionist can ruin our day.

If you are a young autistic person, it could put you off going back to that GP surgery, which could have long-term health consequences. I am very keen that all health and care staff have some level of training, with different tiers and levels of training depending on their interaction with patients. That is why we are consulting on that at the moment.

Jonathan Marron: Health Education England, which looks after training of staff in the NHS, is also working on an autism core skills and competency framework, and specifically at how we train our staff in this area.

Lord Woolf: What does “looking at” mean?

Jonathan Marron: It will produce a competency framework for all staff with public-facing responsibilities, which it is due to publish by the summer of this year. That will be more guidance for the NHS.

Q25 **Lord Woolf:** That will be useful. You have already indicated how important families are and that families should be heard. We have been told that injunctions are sometimes used to prevent parents publicly voicing concerns. Is that something you have heard about or are worried about?

Caroline Dinenage: We do not support injunctions that are in some way to gag families who want to highlight poor patient care. I gave this some thought before I came in. The only reason why anything like that would be in any way appropriate is because the NHS has a duty to protect information that can identify a patient.

There have been some very high-profile cases. The case of Bethany, which a lot of people talk about, was not an NHS injunction. The borough council took it out, and we do not necessarily know why. In fact, it backfired spectacularly, because the case was overturned and now everybody knows about Bethany’s case, and rightly so. The Secretary of State has an inquiry looking into her very case. We are very clear that we do not support injunctions that set out to gag families who are looking to expose poor patient care—quite the opposite.

Lord Woolf: “Quite the opposite” means that you think it is a good thing that parents should—

Caroline Dinenage: The best thing is to maintain good relationships with parents, keep them engaged and keep them informed. If it does not happen, that is where you get a friction and end up with the adversarial relationships that we too often hear about, which are very negative.

Chair: Does that mean that no injunctions have come out from agencies underneath your department preventing parents publicly speaking out about their children?

Caroline Dinenage: There are none from our department. As I say, NHS England may well have done so, but purely out of a duty to protect information that can identify a patient.

Chair: I am just trying to understand in what context this might be justifiable. Just because somebody is a patient does not mean that their parents should not speak about them, does it? Can you give us an example of when might it be justified? Also, how many injunctions are there where parents, according to the health provider, are purportedly breaching patient confidentiality? One person's patient confidentiality is another person's gagging.

Caroline Dinenage: The simple answer to the first question about when it might be appropriate is that I cannot really see a reason either. The simple answer to the question about how many there are is that I do not know, because NHS England runs independently from the Department of Health and Social Care.

Lord Woolf: Should it?

Jonathan Marron: There are two things. Some of the children or young people we are talking about are older, and 16 or 17 year-olds may have their own views on what they would like shared about their care and treatment. There are difficult situations where the family and the individual may not have the same view.

Chair: Is the way, then, for the child to have independent legal representation, and for the child to take the gagging order, not the institution?

Jonathan Marron: Yes, quite possibly.

Chair: If the child is taking it, there are the child's rights. When it is the institution taking it, there is always the worry that it is just more convenient to shut down the parent.

Jonathan Marron: I would go back to the Minister's original position, but this is not a success in any circumstance. We would like to see the NHS and the local authority working with the parents so that people feel they are involved in the care of their family members. That is the right answer.

Chair: Could you perhaps write to us and let us know the numbers? Perhaps leave aside local authorities because they are not directly under your responsibility, but give us the number of injunctions.

Jonathan Marron: We can.

Chair: It might be that there are zero—so much the better—but it would be good if you could give us the actual figures, without a criterion that reduces it to zero because you have decided it is in the interests of the patient, if it is not taken by the patient themselves.

Caroline Dinenage: That is very reasonable.

Q26 **Baroness Hamwee:** I wonder whether I can pursue something that seems to me to come out of that exchange, and the very first exchange, when Harriet mentioned the financial constraints on local authorities. I am not getting a sense of how much co-ordination

there is between your Department, MHCLG, if I have got the acronym right, and local authorities. For some of the responsibilities, the public would not understand who is responsible for what, and the patients and their families must get pretty confused. Can you reassure us that you talk to one another?

On the finances, we have heard about how much less it costs to keep a patient in the community than in hospital. That is an obvious one. It is in everybody's interest to get that right.

Caroline Dinanage: I was with the Autism Alliance earlier today. Its calculation is that to keep somebody in an in-patient bed could cost around £600 a day, which is very expensive to the public purse but nothing compared to the impact on the individual and their family. You are absolutely right. We work very closely with MHCLG on a whole range of issues. It is very important that we do, because any of the social care provided in the local community comes through local government. We work very closely with MHCLG, but also with the Local Government Association and ADASS.

What you are getting at is how important it is to have partnership working at a local level. That is where it really impacts people and where it can be really annoying when organisations work in siloes and jealously guard their own finances. It is the individual who comes out the worst from that. A lot of what we are doing is looking at how we can break down those barriers and how we can provide the services in the community. As Jonathan said, NHS England, as part of the Transforming Care process, is looking at how it can form the skeleton of community services with NHS funding, which can be built on, so that we have those robust facilities in the community. The only way we are going to reduce in-patient numbers is by getting people out into an appropriate community setting, but also by having appropriate community settings that stop people going in, in the first place.

Baroness Hamwee: If I were to ask about timetables and programmes, it would come back to what we were talking about earlier about the Transforming Care programme. Is that right?

Caroline Dinanage: Yes.

Baroness Hamwee: It is in that context.

Jonathan Marron: The Transforming Care programme was deliberately set up to be delivered through 48 Transforming Care partnerships, which are of course groups of local authorities and NHS organisations working together. For this client group, the only way we can do this is by a local authority and NHS joint solution.

Q27 **Baroness Hamwee:** I will come back to what I was supposed to be asking about, which is inspection. Minister, you mentioned CQC thematic reviews. We have heard, and there has been a lot in the press of course, about the conditions in which some young people

are—I was going to say living; it is almost more existing than living.

We have also heard that the CQC may be reinforcing the position by focusing more on processes than on experiences and outcomes. We would be interested in your take on this, whether this is your assessment of the CQC and how the inspection process might be improved to lead to higher standards and higher outcomes and not be a simple tick-box exercise.

Caroline Dinenage: It is an excellent point. As you say, we have this important thematic review, which will be extremely helpful in this. More generally, we have seen a real evolution of the CQC in recent years. There have been lots of changes. There has been a real focus on this sort of thing. You had evidence given by witnesses from the CQC, who will have been able to tell you more about this, but it is very clear to me that CQC inspections must not be tick-box exercises. They cannot be looking at the data rather than speaking to individuals and their families, patients and their caregivers, because they have to have an understanding of what it is like in the setting and what the issues are.

Chair: Can I ask you about the role of parents in these inspections and in the thematic review? To Sally's very important point about the experience and the outcomes rather than the process, they should surely be talking to the parents of those who have children in the institution, but also to those whose children have recently been in the institution but who are no longer there and who therefore might feel more freely able to speak. Do you ensure the CQC has a focus on hearing from parents in that situation? How important is that in the inspection process?

Caroline Dinenage: It is fundamental. It is fundamental to the thematic review. They are talking to service users and families as part of this particular review. More generally, when they are inspecting a service, their evidence will include speaking to individuals on their own, but also in groups. They also use information from complaints. They are able to speak to people who have made complaints, and they speak to user groups. Often, these settings have groups that grow up around them. That is really important.

There is another key part of their work, which is more in the community. There are joint reviews going on between Ofsted and the CQC looking at the arrangements for special educational needs in local areas. There, they engage with parent carer forums. This is all very important to early intervention, which stops the crisis points that lead to individuals ending up in the sort of in-patient settings we have been talking about.

Chair: Bearing that in mind, are you worried about the closure of afterschool clubs and holiday play schemes, which is coming as a result of cuts? I am certainly seeing it in my borough locally, and I know that is not the only example. Talking about early intervention and prevention,

would you be worried about somewhere such as Tuke School, which used to have a really valued holiday play scheme or school holiday club but does not have it any more because it is not financed to provide it? Instead, the local authority commissions a much smaller patchwork service.

Caroline Dinanage: Those sorts of services are really important, for parents as well as the children themselves. I think it goes much deeper than that. We are doing a lot of work to fund mental health support teams that go into schools. The trainees for this have already started. It is going to roll out. There will be 8,000 dedicated mental health support workers in schools in the years ahead. That is to offer that support so that young people do not end up in crisis.

The reason why that is important came up in our autism meeting this morning. Often, the young people you have to be wary of are not those who display the sorts of symptoms we are all aware of. It might be the young girl at the back of the class who is very quiet, who does not say much or present with any particular issues. Nobody really notices her, and she is like a swan, gliding along the surface, but there is a whole lot of panic going on underneath. These are the young women who are later diagnosed as being autistic and may end up in one of these in-patient settings because of things such as eating disorders and self-harming.

That is where we really need to focus: having teachers with the right special educational needs and autism training to identify young people who may be at risk, and having the right mental health support teams in schools. That has been a huge focus for a lot of the work we have been doing.

Q28 **Lord Trimble:** Do the current financial arrangements give providers a perverse incentive for keeping people in detention unnecessarily?

Caroline Dinanage: This is something I have asked myself a lot, and Jonathan will talk about it a bit more. I do not think they do, but there is a lot more we can do in the way we commission services. We are very clear that, if young people end up in tier 4 in-patient settings, it must be for the shortest possible time with a very clear route out. It must be for treatment. That is the whole point of them being there, to support and treat.

We have to look very carefully, and this is what we are doing, at how services are commissioned so that they do not bring in any perverse incentives. The worst possible thing for me would be for any of these providers to somehow warehouse young people and not focus on their treatment and route out.

Lord Trimble: I know you are very anxious to reduce the number of people who are in detention, but the difficulty in getting the numbers down hints that there might be some perverse incentives there.

Caroline Dinenage: As Jonathan articulated, enormous numbers have come out, but the overall number has not come down because we have a whole lot more coming in. That is the biggest challenge: not only to ensure people have a route out of an in-patient setting, but to prevent more taking their place. Did I forget anything?

Jonathan Marron: No, that is right. Our challenge is whether we have the right community services in place either to help people not go into in-patient services or, indeed, to allow a quicker discharge. That is our big problem. The work with NHS England and the Transforming Care partnerships is about whether we can put that effective range of services in place. That is what is holding us back, not an incentive problem.

Q29 **Chair:** What elements are top of your mind when you are worrying about the services in the community not being in place?

Jonathan Marron: On the NHS side, we need a consistent service offer across the country, which includes everybody having crisis services, forensic services able to deal with those and intensive support available. In social care, some areas of the country have very effective markets in provision of high-quality independent living. Other areas are further behind.

The challenges in each place are different. The question is whether we can work with each of the 48 partnerships to get a clear and consistent offer. If you look to some areas of the country, we have good services already with low numbers of beds, effective community services. Other areas have more to do. That is the challenge: how we get everybody to that level.

Chair: It certainly seems to me that I hear endlessly of parents who are asking for an assessment, and it takes weeks or months to get one because the services are just not fully funded enough to deal with the demand. Then, when they get the assessment, they take ages to get the services, because again they are not fully funded enough.

We hear from GPs that they are afraid to ask the questions they know they need to ask, because once they get the answer there is nothing they feel they can do about it without pointing somebody in the direction of a cash-starved system where they are going to have to wait and wait. Is that your sense as well?

Caroline Dinenage: I am very clear that the health system is not cash-starved. We are putting an extra £20.5 billion a year into the NHS. It is the biggest increase in NHS funding, but what will make a difference is having this as a clinical priority. Learning disabilities and autism are now both clinical priorities for NHS England. They have not been previously, and that is going to be a real game changer.

We are reviewing the autism strategy. You will be aware that the Autism Act was the first and remains the only condition-specific piece of legislation in British law. It was introduced by my brilliant colleague Cheryl Gillan, and she is dedicated to continuing this work. This year,

because it is the 10th anniversary of the Autism Act, we are reviewing the strategy and looking at where there are issues and where more needs to be done. That is one of the reasons we had this meeting this morning.

There are some really key things that you have mentioned. One of them is the time between referral and diagnosis. We have heard horror stories that sometimes that can take years. We are setting a clear target of three months. For the first time ever, we are collecting that data. We have been collecting it since last April. From this April, we will be able to publish those delays and hold to account trusts that are not providing that swift diagnosis.

For some parents whose children have low-level needs, having a diagnosis in itself is sufficient, so they can access some of the great community facilities and amazing voluntary sector organisations that are available. For others, that will need to trigger a whole range of other support services, but you need that diagnosis in order to achieve it.

Chair: Can I thank you both very much indeed? This is a 365-days-a-year issue, but in the week in which we are all focusing on autism, it is very opportune for you to have come along and explained so clearly what you are working on. Thank you very much indeed for your explanation and the work you are both doing on this important issue.

Caroline Dinanage: Thank you for having us.