HOUSE OF COMMONS

Health and Social Care

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

Tuesday 27 April 2021

Ordered by the House of Commons to be published on 27 April 2021.

Watch the meeting

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

Questions 117 - 190

Witnesses

I: Bengi O'Reilly, an individual with lived experience; and Dr Sara Ryan, an individual with lived experience.

II: Helen Whately MP, Minister of State for Social Care, Department of Health and Social Care; Fiona Walshe, Director for Mental Health and Disabilities, Shielding and Volunteering Policy, Department of Health and Social Care; Claire Murdoch CBE, National Mental Health Director, NHS England; and Dr Roger Banks, National Clinical Director for Learning Disabilities and Autism, NHS England.

Examination of witnesses

Witnesses: Bengi O'Reilly and Dr Ryan.

Chair: Good morning and welcome to the final evidence session of the House of Commons Health and Social Care Select Committee's inquiry into the treatment of people with autism and learning disabilities. Later this morning, we will hear from the Minister for Social Care, Helen Whately, and senior NHS leaders. We will have Claire Murdoch, who this Committee knows well. She is NHS England's national mental health director. Roger Banks is NHS England's clinical director for learning disability and autism.

Before we hear from them, we are going to listen to two people who have had very challenging experiences of the current system. First of all, Rosie Cooper is going to speak to Bengi, who is the mother of an autistic daughter who has had appalling experiences in in-patient hospitals. Bengi is also a senior nurse and clinical quality manager. Welcome, and thank you very much for speaking to us this morning.

Rosie, over to you to ask Bengi some questions.

Q117 **Rosie Cooper:** Good morning, Bengi. Thank you for speaking with us today. Our best and clearest evidence has come from patients and their families. Please tell us a bit about your daughter's experience of being held in an in-patient unit and the impact that that has had on her and you.

Bengi O'Reilly: Thank you for inviting me to speak today. I am very grateful. I know we only have a limited amount of time. There is so much I could tell you, and so many examples I could give. Some of them are too shocking to be appropriate to share in a public forum. I will very happily have a conversation with anybody outside this meeting.

I am very nervous and anxious about this. I am petrified, in fact, about whether this is going to have a negative impact on my daughter and our family. I am permanently anxious that what I am saying and doing might be misconstrued by professionals—it often is—and I really do not want to make things worse, but I am here because my beautiful, brave, strong daughter wants me to be here. She wants her story told. Sadly, at the moment, she cannot do that for herself, so I am going to try my best to advocate for her.

First, she is currently in an assessment and treatment unit, but the journey to even getting there has been an incredibly terrifying and traumatic process. Back in 2018, we had been waiting for three years, desperately asking for some support with her mental health in the community. There was nothing, absolutely nothing. She continued to deteriorate before our very eyes. She started self-harming. She became suicidal and hit crisis point. Still there was no support. I was ringing every day and begging for support. At one point, I even said, "If you don't do something, my daughter will end up dead or in hospital." There

was no crisis support. We were just repeatedly told to go to A&E, which is completely the wrong environment for somebody who is suffering a mental health crisis, in particular somebody who is autistic and has sensory needs. Given what I know from my professional role and how hard everybody works in my organisation to divert the public from A&E, it seems utterly unbelievable that, as parents, we were being told that was the place to go.

She has been treated like a criminal at times. She has often asked why she is being punished. Autism is very poorly understood. It is not a mental health condition. It is not something that can be cured, and nobody should want to do that. People should be supported to help them to manage some of the comorbidities like anxiety that are very predominant in the community of people who have an autistic spectrum condition.

Our experience is that there is no support for people to stay in the community. There is no choice. You have no voice and no control over anything. There are no local placements. In her latest admission, when she was admitted in October, she waited for 30 hours in ED and then she was transferred to a babies gastro ward, where she was kept in a tiny box-sized bland side-room for four weeks, with no fresh air, no exercise, no stimulation and no activities, and was not able to see friends, family or pets. Unsurprisingly, she had a huge meltdown and started displaying what is seen as challenging behaviour, and there she stayed. We just had to wait and wait until we got the call about where she was to go.

She then moved from the general hospital to a high dependency unit, and from there she was transferred miles away from home. She is currently in a hospital in Wales. That was the only bed. Although we had concerns and we asked for alternative options, we were told that there weren't any and, because she was under section, we had no control. We could not do anything or change anything. We just had to go along with it.

Care has been very variable. There are some very decent people working very hard and delivering very good care in difficult circumstances. Other people seem totally to lack compassion and care. Communication is poor. The way the system works is that it is very disjointed and fragmented. We are left desperately trying to pull things together and to co-ordinate things. We are the one constant in our daughter's life as she is passed from pillar to post and professional to professional. Professionals move on and change jobs. She changes placement. We will always be here, but we are not seen as experts. We are not seen as having valid opinions. The culture of the system is very much that professionals know best, and we just need to conform with what we are told to do. There is no real understanding of autism and how it manifests in the circumstances of somebody being in a hospital. They are then punished for displaying their distress in a way that is seen as inappropriate.

Our daughter has been seen as a problem and a risk, rather than there being a focus on her many positive attributes. There is an incredible need within the system to fit her into a box. That is setting her up to fail. It is incredibly frightening and incredibly stressful. As parents, we have been blamed, judged and criticised. It has been an horrendous experience. Every day, we live in fear and worry about what is going to happen next, and whether our daughter will ever come home.

I could give you so many examples, but I want very quickly to tell you about one time when she was aged 14 and was in a PICU—an intensive care unit. She was desperately homesick and very distressed. I had gone along to visit her. I was on one side of an airlocked door. She was on the other side. She had been quite distressed that morning, so the staff decided that it was not appropriate for me to visit. She could not understand. That was a change to plan. She was expecting to be able to see me. She was looking forward to it. She was deeply, deeply distressed. I will never forget her on one side of the door, screaming and crying for her mum, and me on the other, crying and begging to be able to see my daughter and comfort her. She was physically hauled away and restrained in front of my eyes—*[Witness is crying.]*

Sorry. Going back to the question of what it has been like for us, it feels like our lives have been totally torn apart. Our family has been destroyed. It feels like we are never going to get our beautiful daughter back.

Q118 **Rosie Cooper:** Thank you. Do take your time. It is really distressing. My father was born deaf, and his language was British Sign Language. For his whole life I had to be his voice and ears, and it is a really difficult place to be. Please take your time. It is hard. You see it and feel it, not just for you but for them as well and you have the system to fight. Thank you.

You have described the experience, and how frightening, powerless and, for me listening to it, horrific a situation you were both in. Can you talk us through the challenges you would have in supporting your daughter and getting her out of an in-patient hospital? Did people listen to you? Where was your voice?

Bengi O'Reilly: We don’t have a voice. We don’t feel listened to. This is something that our daughter often reports as well. Like I said, we live in fear every single day. It feels like our daughter has been just swallowed up by the system. She is just a number, a statistic. What is happening to her is not extraordinary; it is very ordinary. It is happening up and down the country every single day.

We speak to several parents. The only support we get is from friends and family and from parents who are also going through this situation. It is incredibly difficult to stay strong and focused, to support not only our daughter but our son, who is just as important. He is still at home. We are trying to give him a quality life as well. The current system is almost impossible. People are not close to home. You cannot see your loved one.

We are told that there should be an ability to do video calls, but that has never really happened. Often the organisations cannot facilitate it, or it is very difficult for our daughter to be able to speak to us in that way. Often, we cannot speak to her by phone. There were periods of time when she had no access to the phone, and we simply were not able to get through on the phone. It was complete radio silence. That is even more frightening.

She is not allowed her mobile phone. Some units have different rules. It is not a blanket rule, but in the particular unit that she is in she is not allowed her mobile phone so we cannot even drop her a text. We cannot send her a cheerful gif or a video to cheer her up. She is completely and totally cut off from her friends, her community, her school, her hobbies, most of her family and, most importantly probably to her, her beloved pets.

It seems like she is out of sight, out of mind. It does not feel like discharge is a significant objective. She has now been in for seven months. We still have no idea how long she is going to be in for, not even a rough ballpark figure. There is no estimated date of discharge. We are not clear on the goals that need to be met for her to be discharged. We have an upcoming planning meeting, and we are very much hoping that that will shed some light on things and help us to get our opinions across a little bit, and help her to get her voice heard.

Too often, the professionals view the barriers, the risks and the challenges instead of looking for solutions and the many positive aspects of our daughter, and the things that she can bring to our society and our family. She has a right to a quality life, just like everybody else, but it does not feel like she has any human rights. She is not treated with any dignity or privacy. She is in a prison-like environment. Everyday things such as getting her hair cut or having physical health appointments are very difficult and challenging.

There is very little understanding of her autism, or her trauma and sensory needs. The environment that she is in is not really geared up a lot of the time to support her with those. Education has completely gone out of the window. She has already fallen quite far behind. It is supposed to be her GCSE year. That was something very important to her, but it has completely gone out of the window.

We have been given inconsistent and contradictory information, which just adds to the anxiety and confusion. We are trying to piece things together, but what we are told does not make sense. It does not fit together. It feels like a battle. It should not be this hard. I have worked in the NHS for years and years. I have dedicated my life to caring for other people and trying to be the best nurse I can possibly be. I now work within quality assurance and improvement for a CCG. I pride myself every day on fighting for the patient voice to be heard and trying to make

things better for other people, but I feel so desperately let down by the NHS because, when we needed it, it was not there for us.

We are seen as difficult and unreasonable. We are told we have unrealistic expectations and that we are hostile. We are trying so hard to work collaboratively with professionals, but it is very difficult to trust them when, quite often, the information we receive is inconsistent. Actions are not followed up, and people do not take accountability. When we raise quality and safety concerns with very senior people in the NHS and in social care and in the CQC, they are not listened to. They are not acted on. They are not believed.

In fact, I reported significant quality concerns to the CQC back in 2018 regarding a unit that my daughter was in at that time. I gave evidence. I listed all the facts and I could back up everything I was saying, but it was never taken forward. Two years later, that unit has just been rated inadequate for exactly the same reasons. That was two years, though, and how many other people have had to suffer in that time?

I don't know what else to say. It has been awful.

Q119 **Rosie Cooper:** That is absolutely dreadful. Would you say that your daughter's experiences are typical of other individuals with autism? On a broader note, what do you think needs to change to give your daughter and people like her the care and support they need? Feel free to speak as loudly as you like because the people who deliver this service are listening.

Bengi O'Reilly: Sadly, I am not convinced that anything is going to change, because nothing ever seems to, but it is good that the right people are finally listening to our experiences.

The quick and simple answer to your question is, yes, I know our daughter's experiences are not unique. I know that they are very typical of the experiences that lots and lots of other people with autism and LD have in this country. I speak for parents up and down the country who report similar experiences. I know, through my professional role, that there are lots of people experiencing these things.

I do not want to get into blame. There are lots of professionals working very hard to try to make things better, but as Einstein said, the definition of madness is doing the same thing over and over and expecting a different outcome. Throwing more money at the current system and trying to improve it is not the right approach. The current system is broken. It is inadequate, barbaric, inhumane and antiquated. We need a completely new model of care. We need a completely new way of thinking and a different mindset among professionals.

In the five year forward view, the Government set what were considered ambitious targets. One of them was that 35% of children and young people would be able to access NHS-funded support in the community;

35% is a dreadfully low target, but that was seen as an improvement. It was supposed to have happened by 2021, but most if not all areas are woefully short of that and unable to achieve it, and 90% of children and young people are not receiving the support that they need. That is particularly difficult if you have additional needs such as autism or LD.

There is a complete and utter lack of community care. There is a complete and utter lack of specialist and LD-specific services. I cannot think of one in-patient unit in the whole country for children and young people that specialises in autism. I cannot think of one. Instead, you just have these general units where young people from completely different backgrounds are thrown together, with different needs, with mixed sexes. In general hospital care, providers are required to report mixed-sex accommodation breaches, but there is no consideration given to these in-patient units, where people are literally living on top of each other in very confined, enclosed, prison-like environments. In fact, that has been one of the difficult challenges for us, given a particular experience that our daughter had when she was 14. It adds to the trauma that she already has.

Without appropriate changes being made and appropriate resources in the community, things are only going to get worse. We know that Covid has had a huge impact on people's mental health. We need to stop viewing autism as a mental health condition, something that is wrong and needs to be cured. We need better training for professionals. They are overwhelmed and under-resourced. Many of the units are run by agency staff. There is a very high turnover of staff, so there is lack of consistency in care. The ATUs are not even NHS hospitals. They are private organisations. The quality of care is completely variable. The standards of care are very low. That is why perhaps some of our quality concerns are not acted on; they are not unusual and there are no quick-fix solutions. There is no way of mitigating the risks of these things happening over and over. Our experience is testament to that, because our daughter has had terrible experiences.

If these hospitals are going to continue to exist, they need to be nicer, kinder, softer and gentler environments. There needs to be more emphasis on therapeutic connection with patients and less reliance on coercion, control and restraint. Restraint needs to be banned. It is absolutely brutal. In the outside world, it would be seen as criminal if five men pinned a scared 14-year-old child face first to the ground and injured them in the process. That would be seen as a criminal offence in the outside world, but it happens in an in-patient unit.

Our daughter has been forcibly stripped and sedated via injection. It is barbaric to do that to a child in distress. There needs to be more frequent review of sections. It feels like there is a lot of drifting. It is very easy to renew a section 3 and then drift for the next six months. There needs to be more accountability and responsibility from the treating clinicians so

that they are answerable for why patients are still in their care and there isn't progress towards discharge.

There need to be better outcome measures. There need to be security cameras to monitor and check on what is happening in the units. The argument is that it would be deprivation of liberty, but these people have no liberties anyway. They are already deprived. They have no privacy or dignity. Quite often, when we have reported things, we have not been believed. Our daughter has not been believed. It is our word versus the staff, and ultimately the staff are always believed and there is no way of proving otherwise. It cannot just be about targets and statistics. It seems that some of those are plucked from thin air. They are unrealistic. They do not mean anything.

The lack of beds in this country tells us the position that we are in. The fact is that we had to wait four weeks for a bed. If that happened in acute general care there would be public uproar, but it is everyday practice in psychiatric care.

Q120 **Chair:** Bengi, thank you so much. We want to hear from someone else, but I have a question about what you said. I want to confirm the horrific story of when you were looking through the glass pane of the hospital door. Was that pre-Covid? It wasn't about Covid restrictions, was it?

Bengi O'Reilly: No. That was pre-Covid, in 2018. Obviously, Covid has made things so much worse. I cannot hug my daughter.

Chair: Understood. The other thing I wanted to say is that later in the session we have top people from the NHS and the Minister answering questions. I know they will confirm that nothing negative will happen to your daughter's care as a result of you giving evidence today. I just want to put your mind at rest on that one, but we will ask them so that it is on the record. I just want to thank you. I think Rosie would also like to thank you for your incredible courage this morning.

Q121 **Rosie Cooper:** I would. Bengi, please do not fear. Not only are you hearing the Chairman's words, but I give you my word. If you need to contact me because anything happens—it won't, but just in case—we will make sure that you are well represented and that your voices are heard. I give you my personal word. Thank you, and God bless.

Bengi O'Reilly: Thank you.

Chair: Thank you so much for the incredible courage you have shown this morning. I think you have really shown people the desperate need for change. Thank you for that.

Bengi O'Reilly: Thank you.

Q122 **Chair:** Please stay on and listen to the rest of the session. Let us know if there is any moment when you want to come in later on.

I now want to talk to another mum I have had the privilege of meeting

before, Dr Sara Ryan, whose son Connor Sparrowhawk had autism and epilepsy. Tragically, he drowned in his bath in an NHS assessment and treatment unit when I was Health Secretary in 2013. Sara had to fight tooth and nail to find out what actually happened to Connor and what went wrong with his care. She has become an extraordinary advocate for people with autism as a result.

Sara, welcome and thank you for joining us. It is very good to see you again. I know you have told me the story before, but could you start by explaining briefly the failings in Connor's care that led to his very untimely death?

Dr Ryan: I think Bengi has just told the story, to be honest. It is a mirror image of exactly what Bengi said, with all the ingredients, except that Connor's unit was only two miles from home.

Connor died in a bath, as you have just said, with two members of staff in an office that was about 8 feet away, doing an online Tesco's order. There were four patients in the unit. It was a specialist NHS learning disability unit with about 24 staff in total. They were specialists, apparently. There were always four members of staff on duty 24 hours a day, and there were five patients. The only treatment Connor had in the 107 days he was in that unit was to change his medication, which increased his seizure activity.

The week after Connor was admitted to the unit as a volunteer patient by us—he wasn't particularly voluntary about it—the CIPOLD, the confidential inquiry into the premature deaths of learning disabled people, was published. It caused quite a furore because it underlined the evidence that people with learning disabilities were dying about 30 years before their non-disabled peers.

I remember being shocked at the report, but did not dream for one moment that it would impact on us particularly, although obviously for the future I was thinking about it in terms of Connor growing older. In the week after Connor died, and before his funeral, the Government response to the confidential inquiry was published. I think that is quite a salutary document for the panel to look at. It captures the ennui or complacency of responses to serious events in this country that impact on particular people. It includes statements like, "The legal provisions in the Health and Safety Care Act will ensure that this problem will be solved," which is a completely meaningless statement; the care Act did not ensure anything, because these Acts are not enforced.

When Connor died and the Government response came out, and the Government—the Chair—said it was too expensive to set up the national mortality review board that the report recommended, we were quite concerned. A week later, the NHS trust board minutes that were published online said that Connor died of natural causes aged 18, in the bath, and that all due processes had been followed.

That rang severe alarm bells for us. At the time, we did not know that another patient had died a week after Connor, of cancer without having palliative care. How you die of cancer in an assessment and treatment unit is quite baffling. At Connor's inquest, we found out that six years before, another patient, having had involuntary ECT treatment, died in the same bath as Connor. We did not know any of this stuff at the time. We were really concerned, because obviously Connor did not die of natural causes. We contacted the NHS chief exec at the time, David Nicholson, and asked him to investigate the deaths in the trust among learning disability and autistic patients, and patients with mental health issues.

This stuff drags on forever, as Bengi has already said; two years after she complained, the unit was found to be failing. The Mazars report was published in December 2015. The findings were absolutely and extraordinarily damning. Only two learning disability patients who died in that trust's care over the space of five years, out of 327 patients who died unexpectedly, had a review of their deaths. That was just one trust.

There was an urgent response to that review, as the Chair will obviously remember. Again, it was like, "The legal provisions in the Health and Care Act will ensure that—". We had that sort of response in the end. It was, "Oh, we'll set up a programme and we'll make things better. Everything is fine."

I have listened to the evidence in these three sessions. Obviously, I have just listened to Bengi. I cannot believe how much more repetition you need to hear. Connor died eight years ago. We are coming up to the 10-year anniversary of Winterbourne View. Yesterday, the inquest into the death of a young woman called Laura Booth finished. She was a 21-year-old woman who went to hospital for an eye operation. She died in 2016, and the box ticked on her cause of death form was that her death was expected, so the coroner was not going to hold an inquest. It took Jayne McCubbin from "BBC Breakfast" to focus on the story to get the coroner to reopen the inquest. Yesterday, the coroner determined that Laura died through malnutrition and neglect—in the 21st century.

I want to put it all into context. We keep hearing the same stories without any context. We need to do something different, as Bengi has just said. Twenty years ago, a group of parents in Oxfordshire who all had children at the same school got together and became very good friends. We have campaigned for our children—well, they have campaigned for their children for 25 or 30 years now. We thought we were pioneering a different way for our children. We thought we were going to give them the life they deserved.

Connor is obviously dead. One of the other young men is teetering on the brink of another repeated admittance to an ATU. He has been bounced to Cardiff, to Lincoln and to Norwich, and yet we are all sitting in this room,

having some sort of—I don't not know what we are having here, really. That is my story.

Q123 **Chair:** You talked about 107 days when he was supposedly being assessed and treated, but he only had one treatment, which was the change of medication. Is the problem with the ATUs? Should we scrap ATUs and replace them with a different model of care that is community based? What do you think is the right solution? I know it has been a long time coming, but just paint a picture of what the care should be like.

Dr Ryan: The problem is that you need to think about how much money you are prepared to spend to sort this out—not you personally. We need to think, but we have no power, us herbs, I suppose. You need to think about how much you are prepared to enforce the regulations that exist, because they are rarely enforced. We saw that with Laura's inquest. Even a coronial process can be flipped if the person is not seen to be human. How much are you prepared to scrutinise that terrible practice, and how much are you prepared to try to shift the attitude towards people with learning disabilities in this society?

Part of the problem is that it is a circular thing. People are hidden away. It is not just people in ATUs. Loads of people with learning disabilities do not have a presence in their community, because they are excluded. When people hear about stories like Laura's and Connor's, they are enraged. It is because it is not on people's radar that much. Look at the thing around the actor in "Line of Duty". People are so keen to see people with Down's syndrome acting, or people with learning disabilities, or Anthony Hopkins getting an Oscar when he is autistic.

We want to celebrate and really embrace all of this stuff, but in actual fact what we are doing is crushing it. These continued reviews, inquiries and commissions, getting people to talk about their own personal experiences and laying their hearts on the table, like Bengi just had to do, are not going to generate anything.

Q124 **Chair:** I want to ask you about Connor's care aside from his death. We just heard Bengi talking about how her daughter was restrained by five men, which sounded absolutely horrific. Did Connor have experience of restraint and poor care in the days running up to his death?

Dr Ryan: The night Connor went into the unit he was restrained by four people for over 10 minutes face down. It was the first time anybody had ever laid a finger on him in his whole 18 years. He was sectioned at that point. I think that, every so often, you might get caught in something; you might feel squashed or something. What sort of impact or trauma does that one event generate for a young person, who was already thrown into some hellhole? Here we are, picking around whether we should stop people being secluded, and should we stop restraint, should we do this, should we do that. We are generating traumatic experiences for people, and then puzzling over why we cannot release people back into the community. It is quite—*[Inaudible.]*

Q125 **Chair:** Do you think restraint and seclusion should be banned, full stop?

Dr Ryan: Yes. There is absolutely no reason why anybody should be restrained or secluded in the 21st century for health-related reasons. We need intensive support teams that work with families or with people in supported living. When they start to have a bit of a crisis, if you had really well-trained people—I know some people who are absolutely brilliant at this—they could work with the person and try to work out what the problem is and what is bothering them: "Let's sort this out."

I know a young person who likes to roam in the countryside. Let that person roam. Support that person to roam and do the things that impact on their wellbeing. You do not seclude and restrain them. You prevent the admittance in the first place.

Some of these places cost £11,600 a week. For that, if we have to have the odd unit here and there, why shouldn't it be like a gourmet menu? Why shouldn't it have the absolute top of the range for that money for those patients? Why can't they have a stately home with space, trampolines and cinema rooms? Why can't we have a few top-of-the-range units and put the money into those, rather than paying £11,000 a week to a private provider to torture someone?

Chair: Sara, I am afraid we are going to have to leave it there. We have a technical problem with the audio on this session. I am going to suspend the session for a few minutes, but I would be very grateful if you could hang on while we fix the problem. I will restart the session as soon as we have sorted out the technical issue.

Sitting suspended.

On resuming—

Q126 **Chair:** Welcome back to the House of Commons Health and Social Care Select Committee. Apologies for the technical hitch. I am now dialling in remotely from my office in Portcullis House, which seems to be more reliable.

We were having two very powerful interviews. Bengi has a daughter with autism, and she was talking about her very powerful experiences, and Dr Sara Ryan was talking about the care received by her son, Connor Sparrowhawk.

Sara, if I may, I will come back to you. There was one final question I wanted to ask. You have talked before about the need for an independent review of every death of a person with autism or learning disabilities in care. Is that now happening with medical examiners, or do we need to go further than is currently planned?

Dr Ryan: It is not happening. I think the inquest yesterday showed how embedded the expectation is that people with learning disabilities will just die early anyway, through the doctors' evidence and the signing of Laura's death certificate.

The LeDeR programme, which was supposed to examine people with learning disabilities and their preventable deaths, was recently evaluated and shown to be inadequate and not fit for purpose. I spoke at the beginning about the call for a national mortality review board. The national mortality review board for maternal deaths back in the 1950s had an exponential impact on reducing the number of maternal deaths we have had.

It seems to me, given all the evidence you have heard and all the evidence we all know, and given the deaths of Connor, of Laura, of Richard Handley and of Edward Hartley, and so many deaths now being brought to light through the live tweeting of inquests—quite a powerful mechanism—we almost owe a duty of care to say, "We are going to set up a national mortality review board, and we are going to scrutinise these deaths and work out what is going wrong and why." These deaths are through things like scabies, constipation, malnutrition, starvation and drowning. These are not deaths through having multiple morbidities, as we kept hearing during Laura's inquest. These are deaths through the fact that medical professionals and health and social care professionals do not see a person with learning disabilities as anything other than somehow a flawed person.

We need to have a review. While we have talked about this on and off for years, I really think we need to do it or we should just pack up and go home and stop even talking about this stuff, quite honestly.

Q127 **Barbara Keeley:** Sara, you have fought for justice for Connor and you have talked about other cases of families fighting even for the justice of an inquest—the Laura Booth case that you just talked about, and finding out that she died of malnutrition and neglect. I should just say that the live tweeting of inquests is very important, but it is terrible that that is moving things forward.

In the years after the Winterbourne View scandal, so many targets have been missed. I have a final couple of questions. Why does the treatment of autistic people and people with learning disabilities in these in-patient settings remain such a human rights concern? What are the main things you would say? I have personally worked for the last three or four years on this. I feel, as you say you feel this morning, that it is just endless. What is the main thing that is keeping it as a human rights issue?

Dr Ryan: It is the establishment really. There was an inquest, maybe before Connor died but I can't remember, about a woman who had put on 7 stone and died in an ATU up north. It was not really of media interest, but the media were bubbling around listening to terrible evidence. When the coroner said at the end, "Oh, she died of natural causes," everybody went away again. It was not important enough to people.

The people in power need to demonstrate the scrutiny that is necessary. Demonstrate that you are prepared to enforce the law when people are

being tortured and are dying. As Bengi said, these things would be criminal acts outside ATUs, and yet everybody is like, "Oh well, this will happen," or, "The LeDeR will solve it." There is a complacency, an arrogance and an ignorance. There are all sorts of terrible things caught up in this.

Norman Lamb tried his hardest to change things when he was a Minister, yet he could not do it. I think we have to say, "Okay, money is not a problem. We are going to do this," and do it. There is no reason why we have such appalling treatment of people in this country in these ATUs, and wider—it is obviously a wider issue; Laura was not in an ATU. There are bigger issues, but if we are just focusing on ATUs, we need to act. We need to sanction. We need to prosecute staff who actually torture people. We need to remove them. We need to get the Care Quality Commission involved. We heard Dr Joyce say that they need to enforce and use the sanctions more regularly. As soon as you start doing that, everybody starts to tiptoe around a bit. Until you do that, this is just going to keep happening.

As you say, Barbara, how many inquests have we followed on Twitter now? Each one has the same issues, which are truly extraordinary and baffling. It is, "It wasn't my responsibility. I don't want to feed her. Oh no, let's push that decision back to next week. We don't want to feed Laura, because of the risk of trying not to feed her once we have started feeding her." These are medical professionals. These are consultants.

Q128 **Barbara Keeley:** At the heart of it seems to be the issue with risk. It is the constant decision making around risk rather than the humanity of caring for the person involved.

Dr Ryan: I don't think it is a risk issue. I think it is a "don't care" issue. It is a "We don't care enough" issue. That is what it boils down to. I do not think that the doctors are really worrying about the risk of feeding Laura. I think nobody wanted to bother.

Q129 **Barbara Keeley:** What our Committee's inquiry is trying to get to is how we cut through the endless reviews and all the fighting that parents like you and Bengi have to go through. How do we shift things? How do we get away from the expectation that people with learning disabilities will die anyway, so let's put it down to natural causes? Is there anything final that you want to say on that?

Dr Ryan: It comes back to the review board. The coroner is going to be asking about Laura's death certificate. Why was "expected to die" ticked? We need to scrutinise those actions. We need to hold people to account. Until we do that, we are just in a circular thing. We need to take action. You need to decide how much we are prepared to spend, how much we are prepared to enforce, and how much we are prepared to scrutinise. As I keep saying, it boils down to that, doesn't it?

Q130 **Barbara Keeley:** As I think you said, placements in ATUs can be

£11,000, £12,000 or £13,000 a week. There are better ways to spend the money that we are spending, aren't there?

Dr Ryan: Yes. Stick people in a suite in the Ritz and see whether their behaviour improves.

Barbara Keeley: Thank you.

Chair: Thank you, Dr Ryan and Bengi for that very powerful evidence. I now want to take that evidence and put it to some of the people responsible for the system at the moment.

Examination of witnesses

Witnesses: Helen Whately MP, Claire Murdoch CBE and Dr Banks.

Q131 **Chair:** For the second panel, I welcome the Minister for Social Care, Helen Whately; Claire Murdoch, NHS England's national mental health director; and Roger Banks, NHS England's clinical director for learning disability and autism. Thank you all very much for joining us.

Perhaps I could start with you, Helen Whately, and ask for your reaction to what we heard from Bengi and Sara Ryan this morning.

Helen Whately: Thank you, Chair. Can I thank Bengi and Dr Sara Ryan for the evidence they have given this morning? It must have taken huge courage to do so. Bengi told us herself how worried and almost frightened she was about the repercussions. I assure her that I will do everything I can to make sure that there should be no negative consequences for her or her daughter through the evidence she has given today. I think it is really important that we hear directly from people like her, Sara and others who have been through and are going through these experiences.

Their stories are so powerful. I know from others I have spoken to that nothing is more powerful. No amount of data, shocking though the data is, for instance, about the relatively low life expectancies for people with learning disabilities and autism, is quite so powerful as hearing directly some of the stories and the awful experiences that families and individuals have had and, frustratingly, are still going through.

I find myself asking, as I am sure others listening today are, how this is still happening in our system. We have known for some years about problems in the system and in in-patient units. There are problems with restraint. An in-patient unit can only rarely be the right place for somebody to be. How is this still happening?

None of us must give up. I would say to all of those who have been giving evidence to this Committee, and who are campaigning on this, do not give up. We must continue to do all that is needed to fix it and to bring about a better system.

The big challenge—I am sure we will get into this in the session—is in part how to do that, and what the better system looks like. We know

quite a lot about what the better system looks like. For instance, it is less often about in-patient care and more often about better community support and making sure that support exists in the community. But how do you get to that better system? How do we make sure that there are the right alternatives in the community? How do we achieve the discharges of people who are in in-patient care long term? How do we make sure that where there is in-patient care—

Q132 **Chair:** I am sorry to interrupt, but could I ask you to tell us what you think the answer is? Clearly, what I tried to do, and what Norman Lamb tried to do, when we were in office, did not work. We did not succeed in getting enough of the 2,000 people with autism and learning disabilities out into community care, which everyone agrees is the best way forward. What needs to change from the approach that we tried to make work?

Helen Whately: It may be helpful to say first—clearly, as you would expect, I have spent some time looking into the data—that we have 2,035 people with learning disabilities and autism who are currently in-patients. That is a decrease since 2015, but it is not the level of decrease that we would have liked to achieve. Since 2015, over 10,000 patients have in fact been discharged from those units. We are not talking about an entirely static population. It is not the same 2,000.

Q133 **Chair:** No. Sorry to cut to the chase, but the issue is that we are still admitting people. You make incredible efforts to place someone in the community. That is too difficult and we need to talk about that, but at the same time people are still being admitted. I think the shocking figure—which I know you are not defending, but it is worth putting it on the record—is that 90% of the individuals in ATUs have been there for more than three months. These are nominally places for assessment and some treatment, but 90% have been there for three months, and the average length of stay—the average—is six years. Six years in a place that everyone agrees is not appropriate is a long-term deprivation of liberty, isn't it?

Helen Whately: I share your concern and the unhappiness you had as Secretary of State about the situation. I know there is a particular set of challenges that we are looking at around the 28% or so who are in these settings for forensic reasons and have Ministry of Justice restrictions on them. Clearly, that is a subset—

Q134 **Chair:** Let's think about the 72% then. Those are the ones that we really can do something about. Six years is a very long time. Let me put to you very directly what Dr Ryan said. Should we not just ban the use of restraint and seclusion? We know that there are better ways of looking after people, using conflict reduction methods and so on. In modern Britain, to have five people on top of a 14-year-old girl, restraining her, is going to make her condition far worse. We should surely find a better way.

Helen Whately: There are two things that I am keen to talk about. One is the question about how we reduce the numbers in in-patient settings, which you were just asking me about. That is a set of work with the title Building the right support. The other is a question about how we reduce and tackle the use of restraint and seclusion. Although they are interrelated there is—

Q135 **Chair:** Let's do them both, then.

Helen Whately: I will try to be brief, and then you can get into it in more detail to follow your interest. On reducing the number of in-patients, we have a programme of work called Building the right support. Last year, I was looking at the work that was going on, and I was frustrated; Claire Murdoch and members of the Department are on this session, and great efforts had been made, but we seemed to be coming across so many barriers and not making the progress that we should be making.

I set up a delivery board called Building the right support—I realise this sounds like a lot of process, but you will appreciate that you have to have process in order to achieve change across a national system. That delivery board brings together all those who are involved in what needs to happen to fix this. It brings together different parts of Government—MHCLG, the Ministry of Justice and Home Office representation—with local government, LGA and ADASS, and with NHS England, of course, and representatives of users. It is so important that families and those who have had—

Q136 **Chair:** I am sorry to interrupt. We want to come on to the restraint and seclusion point. The concern that many people would have, listening to this, is that that feels very similar to the approach that Norman Lamb and I took. There were huge efforts to try to get the bureaucratic wheels moving.

Can I put it to you that actually what we need is a much more dramatic change? We need to look at what they do in Italy. We need to ban the long-term admission of in-patients and say that, if anyone is there for, say, more than four weeks, there has to be agreement by an independent panel on a weekly basis that they can stay in that unit. At that point, the cost of their in-patient care should be made available by whoever is paying for it for community care, so that adequate community care provision can be made. To some extent, following the Trieste model in Italy, do we not need that radical change? What you are describing will be a bit different from what Norman Lamb and I did, but isn't it really more of the same?

Helen Whately: I am aware of the Trieste model. You might want to bring in Dr Roger Banks, who will be able to give more detail on that and is even more familiar with it. Of course, we should, and do, look at international examples, and around the UK, where there are different levels of progress in reducing the number of people in in-patient settings.

On saying that there should never, ever be any reason why somebody should be an in-patient, I guess I would like to see from Trieste and other places whether there is evidence that that really works. One of the things we need to know from Trieste or other examples is the extent to which they succeed specifically with those with learning disabilities and autism.

Q137 **Chair:** But your mind is not closed to doing something like that. Do you accept it?

Helen Whately: My mind is absolutely open. One of the particular strands of work put in place through the Building the right support process is to identify the best support in the community. This is something we need a better answer to. Everyone is calling out, myself included, for there to be more effective support in the community. We heard from witnesses, particularly from Bengi this morning, about the need for there to be more help in the community, but we need greater clarity about what actually works in the community and what the right model is, so that we can then say to every area across the country, "Make sure you have this in place."

Q138 **Chair:** What we have heard on the Committee is that very often people are not transferred to the community because the community provision does not exist. I know that lots of people are going to come back to you, but I want to give you a chance to answer that restraint question, if I may. Do you want to tell me your views on what Dr Ryan said about banning the use of restraint and seclusion?

Helen Whately: Yes. I share the horror of what she and others described. The image in your mind of a teenager being held down is clearly a horrendous one.

The Secretary of State commissioned a piece of work by the CQC—the "Out of sight" report—looking specifically into the incidences of restraint and seclusion. Following the interim report of that piece of work, the set of independent case reviews overseen by Baroness Hollins took place. That has already resulted in some changes to the individual situation for those whose cases were reviewed, and recommendations.

We have recently had the final report from the CQC on that piece of work, with a further set of recommendations. We are already taking action on that, including improving the oversight of commissioning and putting in place specialist staff to support discharge based on the children's intervener model.

Absolutely, there are steps being taken. I think we should continue to reduce and stop the level of restraint and seclusion that we hear about, and know has been happening.

Chair: A lot of people want to ask questions. I will bring in Dr Luke Evans.

Q139 **Dr Evans:** Thank you, Minister, for your comments so far. To broaden it

out, if there is an emphasis towards the community, one of the biggest things is often a disjoint with community care, particularly as young people go into adulthood, because of the age range of 18. We heard some interesting evidence last week that Australia had decided to re-bracket, starting from 12 and then going to 25. Does the Department have any thoughts about how this might be put in place, and what impact such a proposal may have?

Helen Whately: One of the six workstreams of the Building the right support board is specifically looking at transitions into adulthood and how to improve that, recognising, as you say, that there is a particular point when things can often go wrong. I do not yet have the outcome of the work that that group is doing, but we have set up a piece of work to come back and report to the board on what is a better way that we can improve that transition and avoid it being a point of crisis, and potentially someone being admitted as an in-patient.

Q140 **Dr Evans:** It seems that you are looking favourably on that as a position to take, bar the evidence base that comes through. Is it a fair summation of the position at the moment that it is something you would definitely consider?

Helen Whately: I absolutely recognise the problem. Yes, we are considering what is the right way to improve the transition from children's to adult support.

Q141 **Dr Evans:** We heard very powerful evidence earlier this morning. I am going to show my ignorance now. In relation to really adverse outcomes in obstetrics and gynaecology, for babies that unfortunately die, or have serious mortality, there is a review conducted every single time about what happened and lessons learnt, both on a private basis and then that information is collected up as well.

Is there something equivalent for the SAND side, the autistic side and the learning disability side? If not, is that something the Government would consider to really make sure that those cannot slip? We did it because it was so important in maternity care to get it right for adverse outcomes for mothers and babies. It seems like there would be an equal urge for those suffering with autism and learning disabilities.

Helen Whately: As a Minister, I have scrutinised the findings from the LeDeR review and reports. I found those insights really helpful to think about how we can improve the system, improve the outcomes and reduce health inequalities. I absolutely heard Dr Sara Ryan's criticisms of that, and that she does not think that system is achieving what she thinks it should achieve.

My view is that, if the review system we have is not good enough, of course we should look at it. It is absolutely right that we must learn the lessons from every awful incident when things go wrong. That absolutely is the way the system should work.

Q142 **Dr Evans:** Because we are doing maternal deaths and maternal care, as the Health Select Committee, there seems a good parity between the two. If one system is in place, tweaking it and moving it across might be the easiest way for Government to get policy through on an evidence base, because that is what we need, with some tweaks tailored towards it.

It seems an obvious starting point to generate that movement through, with progress that campaigners are very keen to see, without having to go through the rigmarole of changing legislation or re-setting up new consultations. That is the worry; we do not want to see stalling. That is the key message coming through loud and clear through all the evidence that we have seen. We are not talking about stalling on the basis of anyone proactively trying to slow it down, but more due to the fact that, through endless consultations and changing Governments and those kinds of things, progress is slow. What assurances can you give us that progress really is going to be made in this case?

Helen Whately: My view on this is that, if the combination of the LeDeR reviews that we have and serious incident reviews proves not to be providing the information that people feel is needed, we should absolutely look again at the process. Stepping back, my view of the value of these kinds of Committee hearings and inquiries is that, to the extent that we can identify further steps that can be taken, of course we should take further steps. I am listening and will look at whether there is anything further that we can do along the lines that you and others have suggested.

Dr Evans: That is helpful. Thank you.

Q143 **Barbara Keeley:** I want to ask a follow-up question on the issue of the use of restraint, which Dr Ryan mentioned, and even about prosecuting people who physically abuse patients by the use of force.

Minister, you spoke in 2017 in support of the Mental Health Units (Use of Force) Bill on its Second Reading. It received Royal Assent 18 months ago. We have heard from experts who have told us that it should be brought into force to tackle restrictive practices. You supported the Act when it was in the House. What has led to the delay in bringing in that piece of legislation? In October 2020, there were 3,500 restrictive interventions used in the settings we are talking about, and the number might be higher than that. There were 620 restrictive interventions used on children in these units. We have heard about five burly men restraining a young woman of 14. Why can we not move on that, even when we have a piece of legislation?

Helen Whately: It is a really important part of legislation. There has been work going on to implement it—

Q144 **Barbara Keeley:** But it is 18 months since it received Royal Assent. A colleague led it through Parliament, yet it is still not implemented.

Helen Whately: There are two things I can say. One is that the Government have been developing the statutory guidance to support the implementation of that Act, and I expect the Act to commence in November this year.

Q145 **Barbara Keeley:** Clearly, that is not of help to people who were restrained last year and all the children who were restrained last year. I am just pointing out that delays like that do not help, when we have a piece of legislation that would help.

Thinking about what we have heard this morning on these issues, we need to focus on what is needed to drive a change. You mentioned examples of good practice in the community. There are some wonderful examples. There was the case of Bethany, which I raised many times in the House. She has been settled and is happily living in the community, yet in so many other cases, as we heard this morning, that has not happened.

We heard from Ian Birrell that we have a system that is wrecking the lives of autistic people and people with learning disabilities. It seems to me that what we need are people who care—staff, commissioners and everybody who works with those people. We need people who are trained properly in autism and learning disabilities, and people who do not see a person with learning disabilities like Connor Sparrowhawk as somebody who is going to die anyway, so that at his inquest it's, "Let's just put it down to natural causes." There is a complete set of things we need to change, but we are not going to do it through the piecemeal actions that we have seen up to now, are we?

Helen Whately: I have a couple of things to say. First, I have spoken to Bethany's family. You are right that that is an example where a better outcome has eventually been reached. It is absolutely right that we should learn from where we have achieved the right support for somebody outside an in-patient setting.

Coming to your point, totally, we need to make sure that those in the health and care system have the understanding, the training and the skills to provide the right care.

Q146 **Barbara Keeley:** But they don't, do they?

Helen Whately: It has been identified that that is not universal across our health and social care system at the moment. The primary work on this is to introduce the Oliver McGowan mandatory training. That is credit to Paula McGowan, who is a dedicated campaigner on it and brings so much energy to it. She has continued to drive it forward, even against the backdrop of the pandemic, which has made it harder to develop the training programme.

The training is currently being trialled. The pilots will be evaluated, so that we can roll out a truly effective training model across the health and social care system. There is no point in a training model that is not

effective. This is too important for that. We need to roll out an effective model that is not only skills but also the understanding and the cultural change that you will appreciate and have referred to.

Q147 **Barbara Keeley:** That is one aspect of the things I talked about; you need an absolute culture shift. You need a really big change and a lot of drive and leadership from Ministers.

Helen Whately: What I am saying is that of course you want culture change, but you cannot just wish for a culture change. That is why we have a programme of work, particularly the Oliver McGowan mandatory training, to achieve that shift both in understanding and in skills, to give better care to those with learning disabilities and autism.

Q148 **Barbara Keeley:** Can I move on to funding? I want to ask about what plans the Government have to better fund community support. You talked about Bethany's case. You will be aware that in many cases the spending on these in-patient units and ATUs is vastly more than what would support people in the community.

You have committed £25 million a year until 2023 for community services. Freedom of information requests submitted to the Committee by Dr Mark Brown showed that the average cost of supporting a former in-patient— somebody like Bethany—was around £66,000 a year. Your current funding package is only enough for about one in eight people currently in an in-patient unit, and there is no guarantee of funding after those three years.

I do not see any possibility of the sort of long-term planning or investment to get people appropriate support. I put it to you that that funding level is not good enough. If you want an example of what other political parties put forward, my party put forward £355 million. That is much more the ballpark figure you are going to need if you seriously want to move people back into the community. The costs would fall in the end because the community resources would be less than the fantastically expensive in-patient unit costs, but you need some up-front costs to make it happen.

Helen Whately: Barbara, you are absolutely right that in-patient units are very expensive. As we have been talking about, they are rarely the right answer.

There are two things. One is the funding that we have been putting in place to support discharge, recognising that there are particular costs around discharge and often around double running—continuing as an in-patient and then also to fund support in the community. There was funding of £20 million last year that went through to local authorities, and £21 million for each of the next two years that is committed to support that. The feedback I have had from local government is that that is helping them to put services in place that need to—

Q149 **Barbara Keeley:** If I can just stop you there, it is not of the right order.

What I am saying to you is that the funding that you are committing is not of the right order.

Helen Whately: I said there were two things. The second point is that, under the Building the right support work, one of the six workstreams is on funding and funding flows and on what we need to do with funding to support the transition from in-patient to services in the community. Is it, for instance, that the funding needs to follow the patient? What is the right answer for doing that?

I have established a piece of work to look into the funding question. I have yet to have the answers from that because we set up that piece of work right at the end of last year. We recognise that funding is part of the challenge.

Q150 **Barbara Keeley:** I really recommend that you look at the scale. The scale of your ambition is too small. In 2013, NHS England spent £557 million a year on in-patient facilities for people with learning disabilities and autistic people. There have not been up-to-date figures since then. It may have fallen a little bit, but that is the scale we are talking about, so putting through £25 million over three years is just not going to hit it.

Helen Whately: The amounts that I talked about for community discharge are specifically to support the discharge process. Separately, we have a piece of work looking at how we make sure that the funding is in place and at the question of funding flows, so that we have the community services that are needed.

Q151 **Barbara Keeley:** My final point is about autistic people and the Mental Health Act. The planned reforms to the Mental Health Act will see learning disabilities and autism removed as grounds for detention. That is welcome, but we have heard from stakeholders who are concerned that what is going to happen is that people will be detained under the Mental Capacity Act instead. The Mental Capacity Act has significantly fewer safeguards than the Mental Health Act.

How are you going to ensure that does not happen? This is a well-intentioned change that was welcomed by a lot of people, but if it is not going to work because there is just a switch to a different piece of legislation, we are not helping autistic people or people with learning disabilities through that.

Helen Whately: I do not envisage that happening. It is really important, and it is part of the Mental Health Act reform, that those with learning disabilities and autism should not be detained unless there is a specific mental health reason for them to be in a mental health unit, and that any treatment in a mental health in-patient unit must be of therapeutic value. That is absolutely the intention of the—

Q152 **Barbara Keeley:** We know it is not. All the examples we have heard this morning and throughout our inquiry show that there is no therapeutic value. Dr Sara Ryan talked about her son Connor. He was detained and

there was no treatment. In all the time he was in that unit, he did not receive any treatment, and that is just one example. There are thousands of people in that situation.

Helen Whately: I think I have been quite clear. I share with you and others that this is a system that needs to change. There is a set of steps in progress, whether it is through the Mental Health Act reform, the Building the right support work, the Oliver McGowan mandatory training or the all age autism strategy, to make that change happen. It is not simple. These are complex things that involve action across Government and local authorities, with the NHS. There is no one simple answer, but there is a whole load of work going on to make it happen.

Chair: Thank you very much indeed. Let's move on to Paul Bristow.

Q153 **Paul Bristow:** Minister, we have heard evidence about the level of comorbidities that people with intellectual disabilities face. Sir Norman Lamb argued for a new role to be created of intellectual disability physician to better support the physical wellbeing of autistic people and people with learning difficulties. Is this something that the Government are looking into?

Helen Whately: I wonder whether this might be a helpful moment to bring in either Claire Murdoch or Dr Roger Banks, who may be able to give more clinical input on the approach.

Q154 **Chair:** I want to bring them in, but a number of people have questions for you, Minister. We will bring them in shortly. Do you want to respond with your views on what Paul said, and we can bring in the others to respond to the same point in a second?

Helen Whately: I take the approach that we should look at whatever is the best way to improve the outcomes and reduce the inequalities in outcomes and health treatment for those with learning disabilities and autism. As I outlined, the particular focus of the work that I have been driving on the improvement of clinical care has been through the Oliver McGowan mandatory training to improve the understanding of skills across the whole of the NHS and social care workforce. We should also, clearly, look at specialist roles as well.

Q155 **Paul Bristow:** I have another quick question on the distance people are expected to be away from home. We have heard that quite often people with learning disabilities are kept in in-patient settings many, many miles away from their friends and family. What more can we do to make sure that they are placed closer to home?

Helen Whately: First, I agree that we want fewer people in in-patient settings. Secondly, to the extent that you are in an in-patient setting, it is much better that it should be close to home, so that you can stay in touch with your friends and family because that will help you while you are an in-patient and help your return to the community when you are discharged.

There is a piece of work going on for the NHS to look at what is going on in each of the 44 areas. It is called the transforming care partnerships. There is a geography that is delivering the Building the right support and the shift out of in-patient settings. It is looking at each of those areas, what is working in each of those areas and what is not working. One of the things that would be a "not working" example is that there are significant numbers of patients in an area who are being placed out of area, in which case, clearly, action would need to be taken to make sure that there is appropriate care for them in the area they live in.

Q156 **Paul Bristow:** I want to come back to the Building the right support delivery board, which we mentioned a little earlier. It is my understanding that the board meets quarterly for one hour. At the board's first meeting, over 80 stakeholders were invited to attend. How can you be sure that the board will be an effective tool for change?

Helen Whately: That does not sound quite right. The board is not of that scale. It does not involve 80 stakeholders. It is a much smaller number of people. It is actually quite carefully limited in numbers to make sure that we can have an effective conversation, while also making sure that it brings together the different parts of Government, local authorities and the NHS. It is a significantly smaller number than that and meets for what we judge to be the right length of time in order to have an effective conversation—

Q157 **Paul Bristow:** So 80 people were not invited.

Helen Whately: They would not have been invited to the board. We have stakeholder groups that feed into it. It is really important to make sure that that group is drawing on user experience, user stories and what people want to prioritise most themselves as the changes they want to see in the system. We will be listening, but it does not sound correct that 80 people would have been invited[1].

Q158 **Paul Bristow:** Fair enough. How are you making sure that the experiences of autistic people and people with learning difficulties are a key feature on the board?

Helen Whately: We have a group of users who are part of the board and an advisory group that feeds into it so that we make sure that we are listening directly to those with lived experience.

---

[1] Note from witness: The Building the Right Support Delivery Board brings together representatives from Government Departments, local government, Advisory Group co-chairs and other organisations that have responsibilities for elements of Building the Right Support. It is chaired by Helen Whately MP, Minister of State for Care, and met on 3 February 2021. The Building the Right Support Stakeholder Update Forum brings together a wider group of stakeholders, voluntary organisations and people with lived experience to provide additional advice. This Forum took place on 23 March 2021. The Building the Right Support Delivery Board and the Building the Right Support Stakeholder Update Forum will continue to meet on a quarterly basis.

Q159 **Rosie Cooper:** I have a number of questions. Minister, you said that in-patient stay is rarely the right answer. My immediate question to you is, why hasn't it changed? A clue might be the Building the right support delivery board. My query about that board is that, if it meets once a quarter, in which century are we going to produce the answer? There seems to be no urgency.

Helen Whately: The frequency with which it meets has been identified so that work can go on between one board meeting and the next. Progress can be made, and substantial in-depth work can be done so that we make progress. I do not see the value of meeting more frequently in order to somehow look different.

I created that board because I want to drive actual real change in a complicated and complex situation that involves many across our system. One of the things that we know is the most frequently cited barrier to discharge is housing, lack of appropriate accommodation for people to be moved into. That is not something we can immediately shift, but we need a strategic approach, working with local authorities and MHCLG, to make sure that housing gets put in place to overcome that barrier. It is not something that can be done overnight, but we need a decent understanding of why we are in the situation there is with that housing and what we can do to make sure there is that housing and get it to happen.

Q160 **Rosie Cooper:** Thank you, Minister. You will find that quite a lot of those people, including the speakers today, want their children and/or patients home with them, just getting a proper discharge.

There will be frustration and anger throughout the country after listening to Bengi and Sara. Over the years, I absolutely accept, many—including the Chair, Norman, yourself and others—have tried to change the system. You are very sympathetic, but you have failed. Meanwhile, patients remain powerless. Providers are powerful. In this sense, the NHS is acting as an accomplice, and Government are the mechanism. We need to start acting.

The response to the pandemic has shown that, if we really want to do something, we can. We just have to spend the money differently. After some of the answers today, we need to ban or at least monitor in-patient stays and value lives. Minister, what is actually stopping the necessary change, leaving aside an absolute will and determination to make it happen? We have seen from the Chair and others that it is not going to happen unless you do something and act. Stop talking and listening, and act.

Helen Whately: The question you ask—what is stopping it changing?—is in fact exactly the question that I asked last year of the Department's team, who do so much work on this, and the NHS. Why is it that we are still in this situation when, as you say, so many Ministers and others have set out with the worthy ambition to change it?

The immediate piece of work was, "Here is the set of things that are getting in the way of the changes happening." They are lack of support in the community and lack of clarity about what good looks like in the community; problems with the funding; failures over the transition to adulthood; some specific challenges for those who have MOJ restrictions; a shortage of appropriate housing; and gaps in the workforce. There are six things that are getting in the way. Those are the six workstreams of the Building the right support board and the six priority areas. We have, therefore, those six pieces of work going on to come up with, "Here are the things we can do in each of those areas to try to get rid of those barriers and at last make more progress."

Rosie Cooper: Minister, the pandemic has shown that money is no object. If you wanted to spend that money on mental health, you could, and you should. If you spend the money, the other answers will appear. Thank you.

Q161 **Laura Trott:** Minister, we have heard at previous sessions that, despite settings being rated inadequate by the CQC, commissioners continue to buy places in those services. Is this something you are aware of? If so, what action are you taking?

Helen Whately: There are two things. One is the CQC's role. I should talk about some of the conversations I have had with the CQC about what more they can do to make sure that we do not have services continuing to provide care that is inadequate or, worse still, harmful. The other thing is the role of commissioners.

First, I have agreed with the CQC, or support them, taking a tougher approach on those kinds of settings, with an increasing level of scrutiny. We are absolutely willing to close services, and have already closed services down, if they are not providing the care that we would expect, and similarly not to approve new services if they do not look like they are going to fit with the model of care that we want to see.

Q162 **Laura Trott:** Just help us to understand that. In terms of the increasing level of scrutiny, what does that actually look like? What does that mean in terms of the changes that are going to be made?

Helen Whately: When the CQC identify a concern with a service, they will take a more robust approach. They may come up against some challenges in doing so, but they will say that a service cannot continue if it is not providing acceptable care, and alternatives must be found for the people who are in the care of that unit.

Q163 **Laura Trott:** One of the things that was quite shocking last time around was that we heard from Sir Norman Lamb about an individual who was detained in an institution that was clearly providing inadequate and, I would argue, abusive care, and that institution is still operating now. Obviously, you cannot comment on an individual case, but can you give us comfort that this is something that the CQC will be looking at in a more active way?

Helen Whately: As you say, I cannot comment on individual cases, but the CQC has committed and said to me that they are absolutely looking at this with determination. They are determined to be robust and not allow services that are unsafe.

Q164 **Chair:** Laura, could I jump in for one moment to clarify something? I had that conversation with the CQC as well. They said that they did not close down these units before because they were told that there was no alternative community provision. Is the way to solve this to say that, in that situation, the NHS should have a legal responsibility to make the funding that is currently being used for in-patient provision available for community provision?

Helen Whately: I think that is a question that our ongoing work on the funding flows should absolutely look into. What is the thing that we can do with funding that will achieve the objective of making sure that people can be cared for in the community when an in-patient setting is not the right place for them to be?

Chair: Thank you. Back to you, Laura.

Q165 **Laura Trott:** There are two things, Minister, that were highlighted as barriers to the CQC not shutting down institutions. As the Chair pointed out, there was lack of community care. Secondly, Sir Norman Lamb talked about the issue of legal challenges. Is that something you are also addressing as part of the ongoing work?

Helen Whately: The issue of legal challenges has not been brought up with me as one of the biggest barriers. If it is, it is something that we should be looking into. What has been brought up with me is more the situation of the need for alternative care in the community and that we need to make sure that that is in place.

Coupled with that, I want to come to your point about commissioner oversight because that is really important. Clearly, commissioners need to make sure that they are assured about the quality of services that they are commissioning and where they are placing people. Once somebody has been placed in any setting, commissioners need to continue to monitor that they are confident in the care that is being provided.

One of the things that has been identified is that not all commissioners have the appropriate skills to do that. One of the approaches is to improve the training and skills of commissioners. Another is to increase the oversight of commissioning. Both of those things are in progress.

Q166 **Laura Trott:** What sort of oversight of commissioners are you thinking of in that particular circumstance?

Helen Whately: This is to address one of the recommendations from the CQC "Out of sight" report, that there should be unified oversight of commissioning. That is something we are going to work to achieve.

Q167 **Laura Trott:** Forgive me. What does "unified oversight" mean?

Helen Whately: A single point of oversight.

Q168 **Laura Trott:** Does the CQC not perform that role at the moment?

Helen Whately: There is a difference between the CQC role of oversight of services rather than the oversight of the commissioning.

Q169 **Laura Trott:** So a new body will be looking at the oversight of commissioners.

Helen Whately: I would not necessarily say a body. We are working on exactly how it would work. It is a recommendation from the recently published report by the CQC. I cannot go into further detail at this point, but we will be responding in full on that report, and that will be an opportunity to set out more detail.

Q170 **Laura Trott:** So there is an intention to hold commissioners to account for the services that they are commissioning in a more active way than is happening at the moment.

Helen Whately: There needs to be clearer accountability. That is absolutely something we have heard from witnesses today and on other occasions. Accountability needs to be stronger.

Q171 **Dr Davies:** Thank you, Helen. I am interested in your thoughts about how the medical profession can help to bring about the change that is needed. There have been concerns raised over the over-medicalisation of treatment for those with learning disabilities and autism. I wonder whether you feel there is a need for more training and support in in-patient units in particular, so that clinicians can help to push the change, accepting fully that currently community services and housing are often the limiting factor? If there is change from within the system, it is often very helpful.

Helen Whately: Broadly, yes. On the one hand, the Oliver McGowan mandatory training will be required of everyone working across the NHS—doctors, nurses, healthcare assistants and others. Secondly, when looking at the training for those coming into healthcare professions, we are working with the royal colleges and medical schools on appropriate training for doctors, and for medical undergraduates to qualify with those skills already.

Q172 **Dr Davies:** In terms of the in-patient units that are privately run, there is often concern that some of the clinicians and doctors making assessments have a vested interest in not discharging patients under their care, and in welcoming patients. What would you say to that?

Helen Whately: That is a pretty serious accusation of a clinician. We look to clinicians to make the right clinical judgments for people, and they should only admit somebody to an in-patient unit if that is genuinely the right place for them to be and will be of therapeutic benefit for them. Similarly, they should be working to support the discharge of individuals who would be better off being cared for outside an in-patient setting. I

would look to our clinicians to maintain the kinds of standards that we expect of them.

We need to make sure that there are community alternatives, so that clinicians can be confident that when somebody is discharged there will be other care for them, and that there is effective commissioner oversight of the settings where people are being cared for.

Q173 **Dr Davies:** Obviously, as a clinician myself, I would like to fully agree with what you are saying and hope that that is the case, but it has been put to us that independent review of some of those under care might not be a bad move. I wonder, perhaps, whether Dr Roger Banks has anything to add on that.

Q174 **Chair:** I will bring in Dr Banks in a moment, James, but perhaps I could go back to Helen Whately. I think the issue that people are concerned about is a conflict of interest. A doctor may be working for an independent sector company that is getting thousands of pounds from an in-patient bed being filled. The suggestion is that any decision to keep someone in an in-patient unit over a prolonged period of time should be made by an independent panel, and not by a doctor working for the organisation financially benefiting from that care.

Helen Whately: There is a valuable piece of work led by Baroness Hollins—the independent case review—for those who have been in longer-term, segregated settings, for instance, which has been very helpful in looking at individuals. Her recommendations include what should be done to make sure that those individuals are supported to be discharged, including putting in place somebody with a specialist skill to support individual discharge, literally on a case-by-case basis, as you say.

Chair: Thank you. James, do you have any more questions?

Dr Davies: Only if Dr Banks has anything to add on that topic.

Q175 **Chair:** Okay. Let's bring in Dr Banks and then I will go to Claire Murdoch and Dr Banks again because we have some other questions for them as well. Do you want to come in on that point, Dr Banks?

Dr Banks: In thinking about clinicians and decision making, you cannot separate the clinician from the culture and the environment in which they work. Whether or not a doctor is making decisions about retaining someone in hospital on the basis of financial incentives is, I think, more part of working in a culture where there is less incentive to be able to move people on, because of the financial gain.

The Minister alluded to Baroness Hollins's oversight. I think we have a system in place of care, education and treatment reviews that should happen not only prior to admission but once people have been admitted and at regular intervals, to bring a degree of oversight and challenge from a more independent panel. That would always include a clinician who is not connected with the particular facility. Strengthening care, education and treatment reviews, both in frequency, and perhaps in

bringing a greater degree of independent scrutiny, would certainly be a valuable way forward.

Q176 **Chair:** Thank you. Because we had the technical delay, I hope everyone is happy if we run over by 10 minutes and finish at 12.10. I hope people can manage that. I want to have some time to ask Claire Murdoch some questions, and I have some further questions for Dr Banks. I know one or two of my colleagues do as well.

Claire Murdoch, thank you for joining us again. You are a regular at our Committee. Can I start by asking you to guarantee that Bengi's daughter's care will not be impacted by her decision to give evidence to us today? It was a concern that she expressed. I know that you would not want that to happen. I wonder whether you could take that away as something that you will absolutely make sure does not happen.

Claire Murdoch: Can I please reinforce that absolutely? We know that our ability to improve services relies heavily on what service users themselves and the people who love them say. It is absolutely vital that they have not only the freedom to speak up in that way, but the encouragement to speak up in that way. You have my personal reassurance that I will go back to the region and the area and make that expectation clear. I am sure it is already clear, but I will reiterate it and had already determined to do so. It hurts the heart when you hear parents talking about being scared to speak out on behalf of those they love. That should never be the case.

Q177 **Chair:** Thank you; I appreciate it. The last time we met you said that you were a big fan and advocate of the Trieste model, and you hoped to get the number of in-patient children with autism and learning disabilities down from around 200 to 20. That was in the inquiry into children and young people's mental health. Listening to what you have heard this morning about how much more preferable community provision is for people with autism and learning disabilities of all ages, what do you think the main barriers are to stopping that community provision from being put in place?

Claire Murdoch: When we do audits and surveys about what is either delaying discharge or leading to an avoidable admission, there are a few components of great community care. Clearly and above all, good partnership working is essential. For those under 18—let's stick with young people for a minute—you must work with parents, the youngster, education, social care and often, as well, with small, third-sector organisations and others with experience in the kind of support you need.

Secondly, you have to have credible 24/7 community alternatives in place. We are busily building those in the NHS through the long-term plan. As one example, our investment in the long-term plan rises from £17 million a year in 2019-20 to £131 million a year recurrently in 2023-24. Virtually all of that new investment is to support things like 24/7

crisis alternatives, intensive community support and key workers for children and young people.

We are funding and piloting things like senior children's interveners, who will be at least semi-independent of the whole system. They will step in and both look at discharge of those who have been in hospital for a longer period of time and, for example, look in a really challenging way at alternatives to admission. You must have respite and 24/7 crisis alternatives to make it a reality.

Another observation of my own, and I think shared—

Chair: Briefly, if you would.

Claire Murdoch: Very quickly, because I think this is relevant. We know that, as at February 2021, we have 210 young people in specialist learning disability or autism beds. Only 3% of those, or five individuals, had only a learning disability; 83% had only autism. What that has to tell us is that we have made some good headway across the country for young people with learning disability and the alternatives that will support them, but we have to double down on those with autism. We clearly have not got that model right.

For example, this year we are going to invest £45 million in community alternatives. A huge chunk of that £45 million is specifically targeted at 14 to 25-year-olds with autism and what more we need to do to support them in the community. I would like to talk about the provider collaboratives, which I know set up—

Q178 **Chair:** That is very important, but can I ask you, because we are running out of time, to write to us so that we can include information about that in our report?

Claire Murdoch: We will.

Q179 **Chair:** Before I bring in my colleagues, I have a quick follow-up for Dr Banks about the proposed reforms to the Mental Health Act. Will they mean that fewer people with autism or learning disabilities end up being admitted to in-patient units? Will it mean that fewer people are forcibly restrained? Will it mean that fewer people are secluded in isolation? If not, do we need to look at changes to the Mental Health Act so that, either through that or the Mental Capacity Act, we end up with those reductions?

Dr Banks: I think there are aspects of the proposed changes in the White Paper that could certainly help move towards those aspirations. As people have already said, being clearer about the basis on which a person with a learning disability or an autistic person would be admitted, and what the purpose of that admission would be and the expectation of there being therapeutic benefit, would in itself, hopefully, reduce admission and clarify.

There are other things in it that would also be helpful. The duty to have treatment plans aligned to care, education and treatment reviews, which it is also suggested would be on a more statutory footing, gives more teeth and robustness to the process of review and challenge. On the requirement for dynamic support registers, we are already pushing to ensure that every area has a dynamic support register to identify those who may be at risk of admission, and then to be able to intervene quickly. As we know in the circumstances of community care, education and treatment reviews, 83% of those result in something other than admission.

Q180 **Chair:** This is quite detailed stuff, and we would like to make very detailed proposals in our report. Could you write to us with any things you would like to see in the review of the Mental Health Act specifically to help deal with the overuse of restraint and seclusion? That seems to me to be the legislative opportunity that we have. We have heard some terrible stories today. That would be really helpful.

Dr Banks: Of course.

Chair: Colleagues want to talk to both you and Claire. We will start with Barbara Keeley.

Q181 **Barbara Keeley:** Claire, the role of the NHS national learning and disability director has been vacant since December 2020. It is being advertised as a part-time job. That is seen by stakeholders as a downgrade, and they feel it is shown to reduce the priority of the transforming care agenda. Do you share those concerns?

Claire Murdoch: No, I do not. I understand the concerns, and we need to do more to bring stakeholders into our thinking. Whenever a senior person leaves, we look at what has worked in the role, what we need to strengthen and what the next few years look like. It is an incredibly important role. Not all of our specialisms across NHS England have a national director. We have actually appointed a superb person to come into that role, and we are just going through the final procedural sign-off. We have somebody coming in.

What we want to do is step up beneath that person—sorry to be quite so hierarchical; we are a team—and introduce some senior director roles to support them. They will be full time and they have not existed to date. I have personally worked on the mental health agenda as national director for four years. It is absolutely obvious that across learning disability, autism and mental health there are some big overlaps that we need to work on together. I am working much more closely with the programme now, and I will continue to do so afterwards.

There are some brilliant people in the national team who are passionate, committed and knowledgeable about this agenda. They have all stepped into the breach with me since January, including Dr Banks, to make sure that we have not taken our foot off the pedal at all. Further, Simon Stevens is absolutely clear, as is the NHS England board, that we have to

deliver on our promises to 2023-24, and that not delivering is not an option. I am in no doubt that it is a big priority for the NHS.

Q182 **Barbara Keeley:** I think you would find it hard to persuade people that reducing a job to a part-time role is going to improve anything. We have heard about the lack of drive across this whole agenda.

My final point is about the learning from early deaths reviews that Dr Sara Ryan talked about earlier. They are clearly very important, given the tendency at inquests just to say that people with learning disabilities die younger anyway, so nothing is learnt from it. We have to accept that families have to fight all the time. They have to fight at inquests and fight to get a LeDeR review. What can we do to make sure that the learning from reviews of early deaths actually improves services? I think there has always been a tension around that process. It really could help if it were better utilised.

Claire Murdoch: Thank you for that question. I will be speaking to Oliver McGowan's parents on Friday about the training and the learning from his death. Each of these premature deaths is a tragedy. Nobody should be in any doubt about that.

There is a tension between investigating more and the doing. I will be absolutely clear that I want us to do the do, to make the changes. Currently, we have investigated through LeDeR more than 9,000 deaths of people with a learning disability or autism, which is probably the biggest repository of learning anywhere in the entire world. Last year, even during Covid, we managed to get the performance of investigation up to 97% of all deaths.

As you know, we have reviewed the process going forward. We are proposing that any parent or relative who wants a LeDeR review should request one, not fight for one, and have one. All people with learning disability or autism who are black or from ethnic groups should have one. A new addition is that all people with autism should. That is somewhat different from saying every single death. It is because we want to make it easy in every instance where it seems that it will add value for a review to happen, and certainly for parents, carers and family members. We really must focus on action. We probably have the biggest set of learning of anywhere in the world. Now we need to drive major change with perhaps annual physical health checks—

Q183 **Chair:** Claire, sorry. Could we not include every person with a learning disability in care alongside everyone with autism in those reviews?

Claire Murdoch: We could, but it would be a significant extra set of resources. I am not so much talking about the money but about the people resource and the expertise.

Chair: Rather than giving me an answer now, could you look into that and write to us? It is something that Dr Sara Ryan has campaigned on for a very long time as part of the way of shining a spotlight on the

difference in life expectancy that people with learning disabilities have. Rather than give me an answer now, if you could possibly write to us that would be helpful.

Q184 **Rosie Cooper:** Claire, near my constituency there is a range of services for people with mental health and learning difficulties, who are in an excellent NHS secure facility as they are deemed to pose a significant risk to themselves or to other people. It is probably too risky to have them in the community. What do you think those people need in terms of specialist care?

Claire Murdoch: You are absolutely right. Even the Trieste model talks about people with forensic needs or high-risk needs. We need to build on some very good pre-existing expertise. There are some providers of services who are excellent in the field and actually move people through ultimately. We know that, of our original cohorts, not all of whom were forensic, we have discharged 73% of people. Of the remaining 700 from those times, about half of those people—about 350—are on Ministry of Justice restrictions. That cannot mean that they should never move on or step down; it just means that one has to have, although I do not really like this phrase, a pathway of care, where you are clear about how you step people down through the system back to supported, local care.

There are models that are highly effective. It is our hope that we can invest more in those models of care, particularly as we close more beds, where there is a need for in-patient facilities, whether it is for people with a forensic need or those who are highly vulnerable, with multiple challenging behaviours.

I was much taken with Dr Ryan's talk earlier. They need to be palaces. They need to be really excellent, both environmentally and in the clinical offering and so forth. We are about to spend money and invest in a HOPE(S) model through Mersey Care—

Chair: Claire, I am so sorry but we are running out of time. Rosie has one last question.

Q185 **Rosie Cooper:** I think Claire might have been answering it. Do you support the Mersey Care development? It sounds really good.

Claire Murdoch: The Maghull unit development?

Rosie Cooper: Yes.

Claire Murdoch: I had a meeting about it again this week. I have challenged really hard: "Do we need these beds? Who will they care for? How do we make sure there is not mission creep?" They have already allowed us to close 200 beds at Calderstones and to go to about 46 beds on the Maghull unit site. I had a pledge yesterday again from the chief executive that he and his team will ensure that only people with a very serious need are admitted there, and that they will do all in their power to make the length of stay no longer than about 18 months as intensive therapy is provided to them. We are working closely with the CQC at the

moment to make sure that it fits the model of care and that it will serve our populations well. I am delighted that it is already enabling us to move from 200 beds to 46.

Chair: Thank you. There is a last brief question from Luke Evans.

Q186 **Dr Evans:** My question is to Dr Banks. Stepping right back, if we say that autism and disability are not medical conditions, which I agree with, I just wondered what your thoughts are about radically changing the funding formula to say that, given that there is a shift towards the community, in-patient providers should be paid for keeping people in the community and not paid when they are in-patients, on the basis that that encourages the community care to be much stronger. It is a radical change but, from a doctor's point of view, it would be the equivalent of patients paying you when they are well and not when they are unwell because it incentivises doctors to make patients well.

What would your thoughts be? While hard to implement, I wonder if it has some merit in trying to change the emphasis in what we are trying to achieve. Prevention, not cure. Come on, you love it.

Dr Banks: I am happy to do radical, as my colleagues know, provided that the radical is likely to lead to significant change.

The Chair mentioned the Trieste model and others. Talking to colleagues in the United States who have a service called Start, one of the things that seems important in both those models is that people have funding that follows them around rather than sitting with particular parts of the system. They may have a social care budget that follows them, or personal healthcare budgets as in Trieste.

In several places in the United States, there are disincentives to the system. If a hospital does not have a treatment plan that meets the minimum standard, they may not be paid, or will only receive payment for what they are doing. At the end of the contract, the payments might be reduced to provide an incentive to facilitate discharge. I think there are many ways in which we could try to be radical, with different ways of providing funding incentives.

Q187 **Dr Evans:** Do you think that needs legislation, or could it happen organically within the culture of the NHS?

Chair: A brief answer, please.

Dr Banks: It probably needs both. Talking to those—

Q188 **Chair:** We have to leave it there, Dr Banks. I am so sorry. I have a final question for Helen Whately before we wrap up. Thank you, everyone, for staying a little bit longer.

We have been talking a lot about community care and how that is preferable to in-patient care. It obviously needs a well-funded social care system. The Prime Minister told me at the Liaison Committee that there should be a 10-year plan for the social care sector, just as we have for

the NHS. Could you confirm that we are going to see that 10-year plan later this year?

Helen Whately: Yes.

Q189 **Chair:** Thank you. When is the consultation on the contents of that plan likely to start?

Helen Whately: I can confirm the timeline. We have already said in public that we will be publishing a plan later this year. Consultation on that will lead into it.

Q190 **Chair:** I just wanted to check that there will be a consultation process so that everyone will have a chance to have their say as to the contents of that plan.

Helen Whately: Clearly, we want to involve all those who have expertise, views and interest in making sure that we get our social care reform proposals right.

Chair: Thank you; that is very helpful indeed. Thank you for your time this morning. Thank you, Dr Banks and Claire Murdoch for joining us. Thank you, Sara Ryan and Bengi O'Reilly, for your very powerful testimony. It has been a long session, but I think a very valuable one. Thank you, everyone, for your questions and answers. That concludes the session.