HOUSES OF PARLIAMENT

Joint Committee on Human Rights

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

Wednesday 27 March 2019

10.55 am

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Members present: Ms Harriet Harman MP (Chair); Ms Karen Buck MP; Scott Mann MP; Lord Trimble; Lord Woolf.

Questions 13–19

Witnesses

I: Mr Simon Duffy, Director, Centre for Welfare Reform; Dame Christine Lenehan, Director, Council for Disabled Children; Ms Caoilfhionn Gallagher QC, Doughty Street Chambers.

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Examination of Witnesses

Mr Simon Duffy, Dame Christine Lenehan and Ms Caoilfhionn Gallagher QC.

Q13 **Chair:** I welcome you to this session of our inquiry, which is looking at the detention of children and young people with learning disabilities and autism. Half the members of the Joint Committee on Human Rights and are from the House of Lords and half from the House of Commons, and we are concerned with human rights, as the name explains. One of the most important human rights is the right not to be detained wrongfully. Another very important human right is the right to be free from inhuman or degrading treatment. That is the focus of our inquiry.

We have been very concerned about unnecessary detention in assessment and treatment units. NHS England, indeed, has confirmed that some people in these units do not need to be there. We are grateful to you for coming to give evidence today, because you have considerable expertise, so I start by asking you why, when it is not in people's best interests to be in a particular placement, they end up there. Is it because there are more appropriate places for them but the system fails to put them in the right place, or is it that the needs of these individuals are complex, so there is just no alternative care.

Also, what assessment is made, as people continue to be detained, of whether they have been given the right placement? We are looking at where they are detained and how they continue to be detained when that is not in their best interests.

Dame Christine Lenehan: There are groups of children in both assessment and treatment units and in residential special schools who are in full-time placements but do not need to be there. At any one time, at least 80% of the people in placements do not need to be in them either at all or for the length of time that they are there. At the moment, the average length of stay in an ATU for a child aged under 18 is about eight months. Sometimes it is longer than that—up to two and a half years.

Why are these children there? They are there because of repeated system failure. They are often quite easily identifiable early on in the system, but it repeatedly fails. There is something about the level of austerity that is no doubt impacting on the resources to support these children in the community, but even in the days when we had money, children would still be failed and still be in the system. I think it is fundamentally because it is a small group of children. That should make it easy, but actually it makes it really hard.

On the footprint for commissioning and the understanding, we know what model would keep these children in the community and we have seen some good placements showing how to do that, but that model is not routinely commissioned or understood.

What adds to that is that you are taking very unhappy and insecure children and putting them into terrifying placements, and their behaviour

tends to get worse. When that happens, people are frightened. They then end up in restraint, which is unlawful, and physical intervention, which is also unlawful. But the children become so frightened that the clinician's view becomes that the children would not be safe enough to be outside in the community or that the community is not safe. However, it is often the place of detention that is actually making these children more difficult.

One of the challenges I had with my review was when I went to see new clinicians and commissioning officers and asked them what a good post-ATU placement looks like. People did not know. Last week or the week before, we looked at some children who are caught in a revolving door. There is something about understanding the basics, understanding the children and understanding the points of intervention that are successful and then introducing a model of care that meets need.

Chair: When you say that a child does not need to be there, what is the problem with a child being in a place where they do not need to be? Why does it matter?

Dame Christine Lenehan: If you go back to your human rights stance, it matters significantly because it completely and utterly restricts their liberty. These are secure units that are locked. There is no freedom of movement.

Another thing we have found is that it affects a number of other fundamental rights. Children have the right to an education and they have the right to be with their family. These units are often located a long way from home. Let us take Josh, the young lad whose case we followed and who will have given written evidence to your Committee. Josh was placed in Birmingham but his home is in Cornwall. That made it almost impossible for the family to be a family. It took a lot of hard work by Josh's dad to get him out.

When you go into the units, you can see that there is no education system that is fit for purpose. This is about the lack of the right to education and the lack of family life. At root, this is a really expensive use of resources, which means poor outcomes for children, and we have very little evidence that their lives are improved by the sort of scenario in which they are placed.

Mr Simon Duffy: With respect, Chair, you say that there is a choice in putting people in these places, but do people need to be there? The verb is almost the problem, as is the idea of a placement. I worked with some of the families whose children were in Winterbourne View. The pattern that Christine has described is entirely accurate, but the initial problem is often just a small one within the family. It may be illness such as a family member who has cancer. It may be a little crisis to which the system responds in effect with a placement—residential respite or a group home. Then the child reacts in the way Christine has described. They are angry and ask why they have lost contact with their family member, be it their

mother, father or sister. They say, "Why am I in this dreadful place?" There is then an escalating problem.

It is not that we need to commission better placements; rather, we need to start working with families right at the beginning of the process and putting resources and skills alongside those families so that they can design the solutions that make sense for them and their children. We know how to do this, and the centre has many fellows who are working in the field, but that is not where the funding is going and it is not where the expertise is being supported and fostered. We have a system that is fundamentally institutional in its whole approach. As Christine has described, children kind of cascade through these institutions with increasing levels of pain and end up in ATUs.

Ms Caoilfhionn Gallagher QC: I very much agree with what Christine and Simon have said. In my work with children and young people and their families, I tend to see that swingeing cuts to local authority budgets and cuts to child and adolescent mental health budgets have resulted in something that is often seen as a last resort being reached because alternatives are not available and have not been fully explored.

The result is a profound impact on the rights of the individual children and young people who are affected, as Christine has indicated—and not only the right to liberty under Article 5 of the European convention; fundamental issues obviously arise in relation to the right to private and family life under Article 8.

Given the conditions, there are often issues with inhuman and degrading treatment. Many of you may have seen Chris Hatton's blog over the past few days that sets out the horrifying statistics showing how children in these circumstances are much more likely to be subjected to intrusive forms of restraint, for example, than are adults in an equivalent position. There are real Article 3 issues as well.

Chair: Would you explain to us what you mean by the intrusive use of restraint?

Ms Caoilfhionn Gallagher QC: Of course, and I can provide a link to this. The academic Chris Hatton has written a very good blog over the past few days looking at the publicly available statistics. He has found that 12% of children and young people, by which he means those aged under 18—the terminology is used differently by different people—as compared with 7% of adults being detained in in-patient units, experience some form of restrictive intervention. He has taken the most recently available statistics, which are for November 2018, broken them down and found that children are five times more likely to be subject to physical prone restraint, which is a horrifying form of restraint.

Chair: What would physical prone restraint mean for the ordinary person in the street?

Ms Caoilfhionn Gallagher QC: It is being held face down in a restraint position. It is something that my clients have experienced and it is terrifying. It often leads to PTSD and problems later on in adulthood. His statistics are that a child is five times more likely to experience that type of restraint than an adult in the same setting, and seclusion is three times more likely.

Chair: Seclusion sounds to me like a lovely tropical island where you go to be secluded. Are we talking about solitary confinement?

Ms Caoilfhionn Gallagher QC: Yes, that is right. Those are just two examples, but it is worth looking at those statistics because you obviously look at the human rights of adults and children in a very wide range of areas.

Children should have more and better protection, because it should be recognised that, in addition to their rights under the Human Rights Act, children have very particular protections under the UN Convention on the Rights of the Child. That includes Article 37, which says that any form of detention must be a last resort, so there is an imperative to avoid a form of detention; and Article 9, which recognises that separation from family is particularly damaging for children—for under-18s. It is damaging for anyone, at any age, but it is particularly damaging for under-18s, given the evolving capacity of the child.

In that context, when we stand back and look at the statistics we see that, eight years on from Winterbourne View, although there is an overall decrease in the numbers of people with learning disabilities and autism who are detained in a form of in-patient unit, there is a reverse picture for under-18s and a sharp increase in the number of children being detained. Not only is that a fundamental human rights issue for the individual children, but it raises much wider systemic issues about our failures for that group of children.

Q14 **Karen Buck MP:** You have just gone into what you think are some of the factors driving the rise in the use of both restraint and solitary confinement. Can I ask the three of you just to give an impression of the factors, or maybe a single factor, that are driving that?

Mr Simon Duffy: On driving the increase, austerity is a big part of it.

Chair: Is it the increase in restraint and solitary confinement that we are talking about?

Mr Simon Duffy: Yes, in a way it is, because more situations of crisis are being created, as we described earlier. It is perhaps hard to picture. In a system where problems are happening in a family and you are trying to find a solution, there is no flexibility because all the preventive services have been cut—adult social care has gone from supporting 1.8 million people to 1 million in nine years, and children's social care is the same.

So in a sense you rely increasingly on these institutionally funded services, which can often get the NHS to fund them rather than the local

authority, and for children in institutional care you can get regional NHS—NHS England—to fund it. A set of incentives have been set up that mean that, in desperation from the lack of resources on the front line, people reach out for these services. Then the child, who is confused and angry, acts out in an environment that is in no way suitable for them, which is the natural response. It is a bad response, but it is what happens in this kind of environment.

Growing numbers of children are going in as the system fails on the front line, as the education system cuts hit disability education, and as the exclusions grow. These are all connected, and these children are in a sense at the end of the line of a series of failures to support people effectively in the community.

Dame Christine Lenehan: Specifically on restraint and seclusion, one of the big things is the quality of workforce. We looked at a case just before Christmas, which the "Today" programme had picked up, of a child in a children's home rather than an ATU. This child had autism and learning difficulties, and the parents were very angry with the placement, and rightly so. This was a service that advertised itself as appropriate for children with autism and learning difficulties: "We have a specific skill set in this". This young man lost four stone in four months and ended up in hospital with a broken collarbone. That is why someone with an autism speciality went in.

Even on a poorly recorded restraint book—they have to record—this young man had had 200 episodes of restraint within that time. What came out was that the staff just did not understand autism, so people talked to them about basic communication systems for those with autism—the PEC system, symbol systems; really well-known, basic ways to help young people with autism to communicate. We know that fundamentally, with autism, the reaction to violence is often insecurity, and people were reacting by using prone restraint.

Training the workforce is key, but culture is also really important. Once you get units seeing these children as not children but a problem to be solved, you get an increase in the use of restraint.

Karen Buck MP: I appreciate what you are saying, but why has that got worse?

Dame Christine Lenehan: Some of it is to do with a lack of trained staff. We have a huge staff turnover in these units, which is part of the problem. We do not have effective training courses, and, quite frankly, the inspectorate and others now accept standards that are unacceptable.

There is a need for a culture change that is about the turnover of staff and the challenge that children and young people face when they go in. I looked at residential schools that were built for and occupied by a group of children. That group of children changed to children with more complex behavioural needs, but the training of staff and the understanding of why children behave the way they do was not there. While our population of

children has changed, our workforce has not changed, we have cut down on what is possible, and there is the culture stuff. It has fundamentally got worse.

The other thing is that there has been a change in our in-patient population. The numbers have gone up. We started off looking at boys with severe autism and challenging behaviour, but now three-quarters of our girls in in-patient units have autism. They require a different approach and a different way of communicating, and that skill set is missing.

Chair: And if they do not have that skill set, the children end up on the floor being held down.

Dame Christine Lenehan: Yes, if you cannot interpret the behaviour of autism and you do not know where it comes from. If I am an autistic child and I am prone-restrained, I have no idea why you are doing this to me, what I have done or why this is going on. Unless you have a fundamental understanding of what autism does to people and how you communicate and react to it, that will spiral.

Ms Caoilfhionn Gallagher QC: I have a few supplementary points to make. I very much agree with what Christine just said. The issue about the population is critical. The most recent statistics show that 62% of children and young people held in in-patient units are girls, which is quite different from the adult population. I did a recent inquest into the death of a young woman with autism who had had atrociously poor care, and I am very happy to provide you with the findings of the jury and the prevention of future death reports in that case, which may be helpful. There were fundamental problems with understanding how autism presents in girls and with understanding behavioural triggers. This is a real issue: the population and the mismatch between the population and lack of training.

I will pick up on two other factors supplementary to what Simon and Christine have said. First, with many of the families I work with there is a terror about complaining, even when they see bruises, because they are very worried that it may make the situation even worse, and in circumstances where they feel quite powerless. Quite often, I and colleagues of mine who work on these cases find that the parents feel totally at a loss and are worried that if they do something that is perceived as aggressive it will make it worse, particularly when it is a closed environment and they feel that it may be taken out on their child. So the oversight mechanisms are a real issue. There are also issues with the CQC and how effectively, proactively and quickly it responds to indicators of concern.

The second factor is the quality of the workforce. In another very recent inquest that I did, concerns were raised about fundamental cuts to services, because it was a private provider and essentially a business. Again, I can provide you with the material—the findings of a jury, which

are public—and although the context is slightly different the lessons apply here.

Very experienced staff had been removed by a private provider from a care facility that was providing services for young women, including my client's daughter, a young woman with autism among other things. They were replaced with very junior, very young staff, because of the position with the minimum wage, who had had minimal training. At most, they had had training for an hour or an hour and a half, and were then presented with this challenging population. The result in that particular case was that my client's daughter took her own life in circumstances where there was a known risk to her and she simply was not safe.

There is a growing body of evidence. It is anecdotal, because I see it in individual cases so I cannot say whether it is a definite trend, but certainly from my cases I see the same points that Christine has been making about the quality of the workforce and the mismatch between training and the population.

Q15 **Karen Buck MP:** Very quickly, can I ask each of you what your view is of care and treatment reviews? We had evidence that they were not particularly effective. Is there a way of making them work more effectively, such as by putting them on a statutory footing?

Dame Christine Lenehan: We have been working quite hard with children on care, education and treatment reviews. It is important that education is part of it, because we deny a fundamental part of children's lives if we do not have education. We need to look at how they link with education and health and care plans. At the moment, we have this kind of mad-fool standoff, which means that social care does not go to CETRs and health staff will not go to EHC plans because both see them as not important enough, which is total madness.

We know that if you have a good CETR in the community before admission, or pre the possibility of admission, 80% of children who go through that process do not end up being admitted. I have pushed NHS England for three years now to provide me with the evidence of why. I want to understand what in that process is preventing admission. Are we just kicking it down the road? Are we coming up with positive solutions?

I told them again two weeks ago that this is now the most critical information that we need. We need to understand. We have a mad data collection issue in NHS England which means that they collate some CETRs and not others. Pre-admission reviews are collected, community reviews are not. There are some really odd ways of collecting data. Good CETRs with shared accountability across agencies have to be the way forward, but they have to come in at the right time and they have to have the right people who can commit resources around the table. When they do, they work.

Ms Caoilfhionn Gallagher QC: CETRs when done well are obviously a step in the right direction. It is obviously good to have independent eyes

reviewing care. Often, it is a form of assessment that simply has not happened before. However, it is only as good as the available services or the available placement when a placement is necessary. A lot of this ultimately comes back to Simon's point about cuts and what is available. That is at the heart of a lot of the evidence that I think the three of us are giving.

Mr Simon Duffy: I am not sure about the statutory footing question, but speaking more as a practitioner I have tended to experience these formal processes as rather irrelevant to the task of getting somebody out of an institution. That task—the fundamental challenge of figuring out what is going on and helping to design some decent support for them in the community—is really practical. It requires some of the things that Christine has talked about: the ability to understand and to develop communication plans.

Usually, the family is the critical piece—the person, a family. The family knows more than all the professionals put together, but usually it is excluded from the process, sits on the margins of it or, as has been said, is often very fearful. The power balance in these bureaucratic processes does not lead to the solutions that people hope for and associate with them.

If that is what we are trying to do with care and treatment reviews, I am not sure that they are really the tool for the job. I want to understand how that family is empowered and where the resources are to enable that person to be supported. With much less cost than is wasted in the ATU, they could usually be better supported in the community. Where is the support provider who could work with the family to design the support? The commissioning processes have usually ruled them out of the room. The people who have to do the job of providing the support are not even allowed to sit at the table because there is a conflict of interest.

So you get these other things that are to do with the whole culture of social care—the strange marketisation—and that lead to bad thinking around the person. That is what we need to tackle.

Q16 **Lord Woolf:** What would you say about the Care Quality Commission's contribution?

Mr Simon Duffy: I could start with perhaps the most extreme position.

Lord Woolf: I should have said to you that I have a granddaughter who is autistic, so I am particularly interested.

Mr Simon Duffy: The Centre for Welfare Reform has published a lot of material that is very critical of the CQC generally, so I start with a lot of scepticism. If you ask what the empirical basis is for a lot of the CQC's own regulations and behaviour, you see that there is none. It is a strange situation in which you respond to every challenge about quality with more bureaucracy, when we know that there is no basis for that.

I met the families whose children had been at Winterbourne View. It was not the CQC that had led to that, it was "Panorama". Those families said that Winterbourne View had been the least bad place where their children had been. They were not saying that it was good, they were saying that it was the least bad, and CQC did nothing about the others either.

I am not convinced that that is the right way to think about quality. By saying, "We need to regularise this more through bureaucratic processes", you are in danger of normalising what should be unacceptable. In a way, that is what the system does. It starts to say, "Well, acceptable grounds for seclusion look like this. These are the procedures that we would accept for prone restraint". That is not the right approach. We should be saying that this is utterly unacceptable, that people should not be forced to live like this and that we need to design alternative arrangements.

CQC cannot do anything about this. I, is not in its nature to be able to do that. It is not the solution, it is not even the problem, it is just a kind of sideshow. Sorry, that is a little harsh, but I feel that it is true.

Chair: Does anybody have any other views?

Dame Christine Lenehan: When I have looked at services and then gone back to inspectorates, whether Ofsted or CQQ, and said, "I don't understand how you came to your judgment. Please can you explain it to me", they have said, "Go and look at an inspection and see what it is like". So I did. What struck me was that, the way the inspection process is set up, people inspect paperwork and processes; they do not inspect the lives of the people using services, they do not inspect context. "Do you have a book that says how often you have restrained people? Oh, yes, you have a book. Tick".

It is that approach rather than, as you were saying, Simon, something about lives. In a couple of services, I did not feel that any inspectors were asking the right question: "Is this the way children should live their lives? Is this quality good enough? What do we think about it?"

Beyond that, there is really no understanding of market management. If you start to look at the private providers, who have been taking over big time in this area, you see that understanding what a market looks like and our national vision for what good looks like for these children are completely lacking. That is one of the real challenges. Sorry, my view is a bit harsh as well.

Ms Caoilfhionn Gallagher QC: Perhaps I may follow up briefly on the point about CQC and Ofsted which Christine just made.

In cases where there is a serious case review, for example where a child has died or there has been a very serious incident in relation to them, the local authority's children's services when it is Ofsted or the particular placement when it is the CQC will quite often have had glowing or fairly positive reports up to the point of crisis. That concerns me. I have also

seen some very high-quality CQC inspections. One concern I have is that, even when very serious problems are identified to the CQC, including with safety, there is a time lag before decisions are made and actions are taken.

Although this is in a slightly different context, the recent inquest into the death of a young lady called Sophie Bennett is worth looking at on this point. The CQC had produced an incredibly damning report that resulted in most patients being moved out of the placement, with a small number of patients remaining in, one of whom ended up losing her life in an entirely foreseeable accident and in circumstances where the CQC had identified failings months previously.

When the CQC identifies serious failings that relate to safety and fundamental breaches of human rights, what happens next? That is an area where this Committee could make some nuts and bolts proposals. I could provide you with some documentation on that.

Q17 **Scott Mann MP:** Simon, you mentioned that you believe that parents are not involved enough. I am relatively new to this Committee, but I found it odd that parents were not more involved in this process. What do you think needs to change to ensure that parents are more involved?

Mr Simon Duffy: There are some practical and cultural things. It is a long-standing problem. I started working in this field in London in 1990. Coming with no professional training, what shocked me most was that the service system was set up in suspicion of parents. This legacy was associated with the institutions themselves.

Then there are the factors that have been touched on. When, out of love, parents express frustration or anger, the system defends itself from that by "othering" the parent, basically—"The parent is a problem parent. Oh, they do think that, but they've failed their child, haven't they, because why are they here?" You get that whole narrative, which is not an easy thing to solve at all. In a sense you have to empower parents both collectively and in individual situations.

A practical point to make is that the Care Act 2014 and how children's services are developing are just not working at all well. Personalisation was meant to empower families, and there was meant to be clear guidance: "This is the resource you have available because your son or daughter has these needs. We'll help you to figure out the solution that you need". None of that happens. You may, if you are lucky, be given a direct payment but no support to manage it. You then have to improvise some support. Some families do a really great job with that, but for many families it is just not a sensible arrangement.

The commissioning arrangements that were meant to kick in were called individual service funds. They were basically a way of offering a flexible resource, so that if a service provider had to be commissioned or assistance provided in some way, the family could determine that. For reasons that we could go into but it would take too long, over the past 10

years of that personalisation policy those practical commissioning arrangements have not really been implemented at all. To my knowledge, only Dorset has made proper use of individual service funds, which enable families to get flexible support which they can guide and direct, and they can choose the provider. Without that, the families are of course very weak. The system takes control and puts the child or the adult in a place, and the service surrounds them.

In addition, we need to think about collective power. Some fantastic family groups are emerging, but they are piecing together their power in a system that does not provide any resources. It will fund independent advocacy that is not really independent, but it will not fund family advocacy. It will not create any real foundation for the family's voice. It is striking that many other countries have developed much better foundations for families, which means that families feel a lot stronger, their voices become a lot stronger, and the system has to take them more seriously.

Dame Christine Lenehan: Good care, education and treatment reviews put parents at the centre. When the CETR process works, parents are at the centre, but when it does not, they are not.

The biggest frustration I have found for the parents of children in ATUs is that, by the time their children have landed in one, almost every parent is seen as a problem for the reasons that Simon has explained. As parents challenge the system more, the system reacts by hiding. What works best in the system is when confident professionals work with confident parents on solutions and are open, honest and transparent.

One of the recommendations that I was trying to get through two years ago and is now coming up in the long-term plan as agreed, but only in five years' time because there is no money—so it is unicorn decision-making at the moment—is that families will have a key worker. We were seeing children going into an institutional system and their parents being given no single point of contact.

That to me is basic abuse. There should be a single point of contact so that parents understand what is going on with their child, what the treatment options are and what options are available after discharge. Parents should be able to question someone appropriately. Instead, at that level the system shuts down and says, "These people are too difficult to deal with". People see the parents as complex, not the children, and see them as part of the problem, not the solution. When it works, of course, it is brilliant. What is missing is standing up and taking account of what is going on.

Ms Caoilfhionn Gallagher QC: I want to make three points here.

First, on the single point of contact, I often see in my cases that parents are left with an information gap—there is radio silence—so although they are supposed to be notified of key developments that have happened on

the ground, they are not told. That, of course, undermines their ability to challenge, question and press.

Secondly, on the "difficult parent" culture, I very much agree with the points that the others have made. My client Sara Ryan, Connor Sparrowhawk's mother, has written very powerfully about the culture of mother blame and the perception of her as being difficult. When we looked through many of the documents from the inquest, you could see that when she raised points, on which she was absolutely right, she was belittled, sullied and criticised, and she was perceived as just being a hassle who was interfering with the ability of the staff to control her son in the way they thought should be done. An extreme example of that is obviously Bethany's case, in which Radio 4 became involved. There is an assumption that the parent is being difficult rather than the parent having their child's best interests at heart and speaking out.

Thirdly, I am conscious that a recommendation was made in the Mental Health Act review about advocacy services expanding to include parents and carers, including informal carers. That may be worth giving a little more thought to so that there is a recognition of the role that parents and carers play in the process, because at the moment they are perceived as troublesome outsiders a lot of the time and are not valued.

Scott Mann MP: When the relationship between the provider and the parent breaks down, what options are available to the parent to complain about or raise concerns about the service? Do you think that the system we currently have in place is adequate for the complaints process?

Ms Caoilfhionn Gallagher QC: There are real problems with it. I mentioned earlier the concerns that many people have about using it. Although in theory mechanisms are available to them, they are worried that in the circumstances they will make matters worse. In many of the cases I see, people have turned to litigation as a last resort. Again, that can be difficult and time-consuming, and in a lot of cases it does not actually improve matters on the ground promptly. The mechanisms that we have available are crude, but a lot of it goes back to the cultural problem, because some of these things are very simple to solve.

Mr Simon Duffy: Practically, it is not clear to me why, in almost all cases, the family does not have clear rights to determine where the appropriate support is and to terminate support packages. That is what a good commissioning system would deliver. It is not a matter of looking on while the system determines how your child is supported. It is about you deciding, so that when you see that something is wrong you terminate it.

That would make a big difference to the power relationships and is perfectly achievable. We have achieved it in small areas, but for reasons that are largely to do with systemic failures by the Department for Health and Social Care to set appropriate guidelines for commissioning, local authorities have continued to fall back on the placement model whereby

they take back control and the parent is left at the edges. That is an utterly solvable problem. If the Care Act 2014 and the principles of supported decision-making were properly applied now, families would be in a much more powerful position.

Ms Caoilfhionn Gallagher QC: There is one thing I should have said. Sometimes—not very often—I see the rights of the child used to argue that the parent should not have any involvement. Of course, there may be situations, particularly with a capacitous child, a child who is older, where there may be a conflict between the interests of the child and the interests of the parent, but that is sometimes used as a fig leaf to explain parents having no involvement at all, and in fact when you go through the material it is quite clear that the child has given consent for their parents to be updated about developments.

As I say, it is a fig leaf and it is not right. It is important to note that there may in some circumstances be a distinction between what the parents want and what the child wants, and it is important that that is recognised, but that is all the more reason to have a more nuanced system instead of a "parents are outsiders and they are interfering" approach.

Q18 **Scott Mann MP:** I have one final question that I shall bundle into two. We know that injunctions or gagging orders are sometimes used to prevent parents publicly voicing their concerns about the treatment of their children. In what circumstances would those orders be sought, and are guidelines in place to ensure that they are used only when necessary and are not misused?

Ms Caoilfhionn Gallagher QC: One of the problems is that it is very difficult to know how prevalent they are. Obviously we have seen the extreme example of Bethany's case which then comes to court. There was another relatively well-known example from 2005. But apart from those there is a real open-justice issue about how often they are sought and what happens.

So I am afraid that I cannot help the Committee with how prevalent such orders are. I have checked with a number of my colleagues who are specialists in the area. We know that Bethany's case is not an isolated one; there are other recent examples. The numbers are relatively low, but I can provide the Committee with more detail if that would be helpful.

In Bethany's case, of course, simply because her father speaks and writes so powerfully and had spoken out, there was support from specialist lawyers who were willing to provide pro bono assistance as well as support from media organisations, so the case was fought. However, in many cases this happens much more quietly, and people are silenced in ways that never see the light of day, so we do not know.

On guidelines, depending on the type of order that is sought, if a form of reporting restriction order or some other form of order is sought, there are not guidelines as such but there are precedents in the cases. I am

less concerned about that, because when they get to court, as we can see in Bethany's case, you can get the right result. I am more concerned about what happens when they do not see the light of day and it happens more informally at an earlier stage.

Q19 **Chair:** I think a lot of people would find it hard to work out in what circumstances it could be right to stop a parent speaking out. If you are talking about injunctions for parents who are physically assaulting staff, everybody would understand that, but we are talking about parents voicing concerns.

Can you explain, from the other point of view, where it would be right, in the public interest and in the child's interest for an injunction to be taken out? Also, bearing in mind the paucity of evidence, the fact that the person seeking the injunction is obviously not likely to broadcast it and the person at the other end of the injunction is not able to speak about it, who should be gathering the information so that we can work out how prevalent it is? Also, argue for an injunction against a parent.

Ms Caoilfhionn Gallagher QC: I will not do that, because, wearing one of my other hats, I am an open justice specialist.

Chair: So you do not think there is ever a justification for it.

Ms Caoilfhionn Gallagher QC: I am not saying that. Of course, there may be some quite extreme circumstances where it could be justified, depending on the facts of the particular case.

Chair: Give us a "for example", because some of us will find this quite difficult, bearing in mind freedom of speech and parents' rights. If somebody says something that is not true, it is not usually responded to in an injunction financed by a public authority. Just explain why these are there.

Ms Caoilfhionn Gallagher QC: Ordinarily, I do not mind being a devil's advocate, but I am afraid I am struggling, particularly in relation to a blanket-type gag order. Of course there may be circumstances where you weigh the very powerful Article 10 public interest in freedom of expression in this context—this not only relates to the individual parents' rights; there is an often a very powerful public interest, as there was in Bethany's case, to do with the wider cohort of children in these circumstances—against the Article 8 rights of the child.

I can certainly see circumstances where some particular information could be overly intrusive to provide, such as information that is particularly intimate about the child. But when it comes to speaking out about the fact of detention or the types of conditions to which the child is subjected, I struggle to see a circumstance in which a blanket gagging order is likely to be Human Rights Act-compliant.

Chair: Does anyone else want to give us examples of where, in your view, an injunction would be justifiable to stop a parent speaking out?

Mr Simon Duffy: Again, I cannot be very helpful. The memory that comes back to me is that of one of the first families I hoped to get out of an institution. It took ages to get the right to speak to the family because it was so stigmatised by the system. Eventually, when we got to meet the family, we could see the possibility of a solution. We went for our first meeting at the institution, which had a meeting room that was about the size of the space here. When the parents and I arrived at this meeting, all the professionals were already filling all the seats in the room, and they left no space for the family.

That visual metaphor is my constant experience. I just do not have this experience of families trying to exploit the system. There is a tiny percentage of abusive families, which is a real problem in itself, but they are not the ones running around doing this. We have a system in which families are systematically discriminated against and their voice is not being heard, so it is really difficult to get into the head of somebody who wants to impose a gagging order, I am afraid.

Ms Caoilfhionn Gallagher QC: I am afraid that I am a lawyer, and I struggle to see when that legal mechanism should be used.

Chair: Just to pick up on what you said, have I got this right? Although not in every case, when things start to go wrong, parents are then failed by the system; they are marginalised and become stigmatised and fearful, and they are then resisted and are powerless. Is that it?

Mr Simon Duffy: Yes.

Dame Christine Lenehan: Yes. That is a good summary.

Chair: Then, on the other side, you are saying that the remedy for this is that they have to be part of a decision-making process, but you are describing something that is very binary: the parents have all the responsibility for the child, and then suddenly we take over, make all the decisions and shut them out. So we need to be not so binary on this.

Mr Simon Duffy: Yes. It is almost doubly binary, because just in getting to the nitty-gritty of social care provision, if a family says, "Okay, we'll try to figure it out", the mechanism of a direct payment is used, which transfers some financial resource to the family but does so in a way that also loads all the responsibility on it and does not provide it with support.

We do not equip ourselves to deal with all the subtlety that you need to provide good support, particularly for the folk who are most complex, whose behaviour is harder to read, and who are not coping with the world in quite the way other people are used to. We need good expert advice; you cannot just say, "Oh, just leave it". The reason you are even in the room is because the family is calling out for help. But it is not calling out to be completely disempowered and ignored.

Chair: So basically the solution, then, is for them to be kept informed, including with a key worker for family contact, and for family groups to

be funded. One of the things we have been amazed at is how these individuals are not only dealing with their own child's situation, often very bravely and apprehensively, but are also working with other parents, although without any support for that.

Mr Simon Duffy: They should not just be kept informed. The default commissioning option should be that they are in control. We have systems to make that completely feasible now, without any legal changes. Better guidance from the Department of Health and Social Care and better practice in local authorities now could put families in the driving seat for the development of most of the support and services that they and their children receive.

Chair: Thank you very much indeed. Once again, thank you for being prepared to come to see us at a different time. Obviously, we have significant Brexit decision-making later on in the day, but we regard this as incredibly important. We did not want it to become a Brexit casualty; we wanted to hear from you and to press on with our report. We are grateful for your flexibility, for the expertise you have shown in your evidence to us, and for the work you do in this significant area. Thank you.