HOUSES OF PARLIAMENT

Joint Committee on Human Rights

Uncorrected oral evidence: Human rights of children in the social care system in England (HC 1218)

Wednesday 10 December 2025

3 pm

Watch the meeting

Members present: Lord Alton of Liverpool (Chair); Juliet Campbell; Lord Dholakia; Tom Gordon; Baroness Kennedy of The Shaws; Afzal Khan; Baroness Lawrence of Clarendon; Lord Murray of Blidworth; Lord Sewell of Sanderstead; Alex Sobel; Peter Swallow; Sir Desmond Swayne.

Questions 35 - 44

Witnesses

I: Alex Ruck Keene KC (Hon), Barrister, 39 Essex Chambers; Professor Alison Young, Commissioner (Public Law and Law in Wales), Law Commission; Connor Johnston, Senior Lawyer, Law Commission.

Examination of witnesses

Alex Ruck Keene, Professor Alison Young and Connor Johnston.

Q35 **Chair:** Good afternoon and welcome back to today's hearing, which is the 38th hearing in this session of the Joint Committee on Human Rights. We are looking at the position of children with disabilities who are in social care.

On our second panel today we are really pleased to have Alex Ruck Keene KC, who is no stranger to this committee. He is at 39 Essex Chambers, where he is a practising barrister, but is here in a personal capacity today. He is a professor of practice at King's College London. He has appeared in leading cases concerning deprivation of liberty and the ability of children to consent to treatment. In the past, he was a specialist adviser to the Joint Committee on Human Rights for its inquiry into human rights of those in care settings, so it is very appropriate for you to be here today. He was a consultant to the Law Commission for its recent project on disabled children's social care. As I have said, he will be giving evidence in his own personal capacity.

We are very pleased as well to have Professor Alison Young, who has been the law commissioner for public law and the law in Wales since March 2024, when she took up that role. That is a five-year post, as I understand it, working on law reform in public law. Prior to that, she served as a legal adviser to another parliamentary committee of the House of Lords, the Select Committee on the Constitution. She is the Sir David Williams professor of public law at the University of Cambridge, a fellow of Robinson College and an academic associate at 39 Essex Chambers.

We have asked them if they would bring some back-up reinforcement in case it is necessary in the course of the afternoon. We are particularly pleased to have Connor Johnston, who is a senior lawyer at the Law Commission. Connor is the senior lawyer on the law in Wales team at the Law Commission. He was the lead lawyer on the disabled children's social care project for the duration of the review from September 2023 to 2025. He is a barrister and door tenant at Garden Court Chambers.

Welcome to the three of you. We are very pleased to have you here. As you know, this is an important inquiry that is being conducted by the JCHR. We will report next year and your evidence will help us to frame our recommendations, so thank you for that. Let me ask a first question before I turn to my colleague Lord Dholakia. That is to ask you to give us an overview of the legal framework applicable to disabled children in social care. Perhaps you could explain to us whether there is a case for reform and improvement.

Professor Alison Young: Thank you very much for inviting us and giving us a chance to talk to you about our most recent work on disabled children's social care. When you are trying to understand the legal framework, it is important to recognise that there is not a one-stop shop

where you can go away and find the law specifically on social care for disabled children. You find that the law is split between those provisions that focus on people with disability and those provisions that focus on children.

You have Section 2 of the Chronically Sick and Disabled Persons Act 1970, which is where you get duties referring to the need to look after the welfare and provide the needs of those with disabilities. Then you have Section 17 of the Children Act 1989, which defines the way in which you provide care for the needs of children in need. Disabled children are part of the children who are defined as being included as children in need. You end up with two different duties that are then supplemented, as you heard in the previous evidence session, with a whole series of different aspects of guidance. Then you have case law, which adds on to the law, which sometimes will make you realise that what might not necessarily look like a duty on the face of the law is a duty when you interpret it in line with the case law.

As you can probably understand from that overview, you have a bit of a mismatch of different provisions. It is a bit of a patchwork. It can be very difficult to navigate. That means that it can be very difficult for those with children to know where to go to get help and assistance. Parents and carers of disabled children might not know how best to get access to what they need. It also means that those providing those services will often find that they are navigating a different system in order to do so.

Because of this element of fragmentation of the law, we felt that it was very open, as a case for reform, to try to make the law more accessible and, in doing so, make it easier for individuals to be able to protect their human rights in those particular circumstances. We also felt that there was a need to modernise some aspects of the law. You heard in the earlier session about how some of these definitions are out of date and need to be updated. In all those aspects, we felt that the law was not necessarily being administered in a way that was fair in terms of understanding the postcode lottery and the lack of national criteria. There is a need to draw together different elements of fragmentation and modernise the law as well.

Chair: That reinforces what we were told in the earlier session about how much of the law is antiquated and needs change and renewal. I am sure your colleagues would like to add to that.

Connor Johnston: I will start by building on one of the points that Professor Young has made, which is about the inaccessibility of the law. To respond to the point made by Mr Sobel earlier, the accessibility of the law is a core component of Article 8(2) of the convention and, in this case, it is not remotely accessible. One difficulty we had in writing our consultation paper was that there is no single resource, textbook, case or piece of guidance you can look to to find out what the law is. This is an area of law that is principally needed by families and social workers. These are people who, in the current situation, have to navigate an

incredibly complex and patchwork system. That in itself is an incredibly important factor militating in favour of reform.

The other point, touching on one theme from the earlier part of the session, was this theme of what is referred to in the academic literature as parent blaming. It is the idea that there is sometimes too much focus on safeguarding children from harm rather than meeting the additional needs arising from their disability. The particular instances we heard again and again during this review of where that occurs are families asking for help for their disabled child and being made to feel as if they have done something wrong through actions such as checking bedrooms, fridges and mattresses and interviewing children without parents.

When these things happened without any evidence of harm or abuse, or risk of harm or abuse, to the child and without any explanation to the families, they left families feeling that they were navigating a system that was set up for child protection and not support in human rights terms. To finish, the problem here is that we end up in a situation where there are disproportionate and unnecessary interferences with family and private life.

Chair: We seem to swing from one extreme to another.

Alex Ruck Keene: One observation is that, in large part as a consequence of how the law is incredibly complicated and messy, people just do not understand it at all, including, I should say, within the Department for Education. For instance, programmes such as family help and early help are thought to be very important ways in which to intervene early in the life of a situation before it gets high, as it were, but there is this continuing myth that it is extra-statutory assistance. That rather fails to grapple with the fact that local authorities are creatures of statute. They cannot do something unless they have statutory powers.

Because we now have a system that is incredibly complicated, there are bits where there is a perception that, "You really do not want to get into doing a Section 17 assessment. Let us say that it is extra-statutory", when, as a matter of law, it is not extra-statutory at all. It is just a very light-touch assessment. We have things where people are trying to do the right thing, but actually leading themselves, inadvertently, into some very complicated legal terrain. That is all, as it were, absolutely fine if it does not have any impact on anyone. It is extremely serious if it has an impact, because you do not know how you are supposed to be thinking about it and challenging it.

Chair: That is very interesting. It sets the scene very well for the other questions that my colleagues have for you.

Q36 **Lord Dholakia:** My question follows on from the very question that was put to you. To what extent are human rights principles embedded in the legal framework applicable to disabled children's social care? If not sufficient, what sort of suggestion would you be making?

Professor Alison Young: As with most aspects, you have a piece of legislation that is designed to provide a way in which, in practice, you can uphold the rights, but you do not necessarily get it, within that specific provision, saying, "Here are the rights". As usual, you have the Human Rights Act, which is a way of recognising how local authorities have a duty to act in line with convention rights. Mostly here we are thinking about Article 8, which is the right to privacy and family life, combined with Article 14 to make sure there is not an element of discrimination. You also have Section 3 of the Human Rights Act 1998, which imposes duties to interpret these provisions in line with human rights. As you have been hearing in the previous session, there is an element of training that can be done from a human rights angle.

It is one of those situations where you have the Human Rights Act as a framework in which you understand the human rights context. These particular legal provisions are ways in which you try to ensure, in practice, you can uphold those rights, interpreted against that background, with hopefully some training to bring it in.

Chair: You are reinforcing the point that was made again earlier in answer to Lord Sewell about the training of people so that it is not just writing it down on paper. It is ensuring that people know how to do it.

Professor Alison Young: Absolutely, yes. It is very important to ensure that individuals who are administering social care understand that framework and can do so in a way that upholds rights.

Connor Johnston: It is fair to say that, on paper, human rights are embedded in this system. They are front and centre of it. Section 2 of the 1970 Act was an absolutely groundbreaking piece of legislation. It was one of the first statutory provisions to give rights directly to disabled people to have services and to enable them to participate in society and on equal footing. Lord Alf Morris described them as essential lifelines to allow participation.

Section 2, viewed through a human rights lens, is about securing Article 14 rights. It is delivered under Section 17 of the Children Act, which is a way, expressly, according to Section 17(1), of keeping families together. That is a means of promoting family life. It is there on paper, but, as you have heard previously and will have seen in our report, it is not always operating in that way in practice.

Alex Ruck Keene: I will make one observation in relation to training. It has very much taken me back to the previous inquiry that I had some role in on the human rights in care settings. I was extremely struck at that point by the resistance by organisations to having training that expressly mentioned human rights. They kept going back and saying, "It is alright because we embed them". I am paraphrasing, but that was the strong sense I took away. You are embedding the idea that human rights are in some way alien and different to what you are doing. You are thinking, "I am now doing something different because I have to think about human rights".

There are organisations, such as the British Institute of Human Rights, that do training in a way for health and social care professionals so that they actually see, "This is what I am doing. This is how I am balancing human rights, positive obligations and negative obligations. This is what I am doing. Oh, I see. It makes sense". Watching people who have been through that and how they approach things is so different from seeing someone who has had quite a blanket "Here is some human rights training" and it just feels completely detached. When you are thinking about training, it is how you get that message across.

Chair: Can you give us any idea of how many people would have done that kind of training and therefore made the difference and those who would not? Do you have a rough percentage, even?

Alex Ruck Keene: BIHR is a tiny charity. It does an awful lot of work and it is commissioned to do things, but there are only so many people. It is that model of thinking, as opposed to saying, "We are going to roll out web-based human rights training", which, to be honest, I do not think really does anything, or having stuff where you say, "This is all embedded and we do not need to mention it", which is fine if it is genuinely embedded.

Q37 **Sir Desmond Swayne:** Is the current definition of a disabled child inconsistent and outdated? Ought it, as the Law Commission suggests, be replaced by the Equality Act 2010 definition, which is, for the avoidance of doubt, that a child has to suffer from a physical or mental impairment and that that impairment has a substantial long-term adverse effect on their ability to carry out normal day-to-day activities?

Professor Alison Young: Yes, we felt that the current definition of disability is out of date. If you look at the wording of the Children Act, it refers back to an older definition of disability. It refers to things in language that we would now consider to be offensive. For example, it refers to people who suffer from mental disorder of any kind or someone who is substantially and permanently handicapped by illness, injury or congenital deformity. This is not the language we would use now to understand meanings of disability. It is very important to think about the language we use and the message that that is sending to disabled children. It is very important to modernise and update this.

The other problem that we have is that this definition does not tally with the definition of disability you find in other areas of the law. That can give rise to disparity and fragmentation. Our recommendation with regard to updating was not just to update it, but also to bring it in line with the definition that you find in other areas, so, for example, with the SEND provisions, which rely on the Equality Act definition, which you established.

We think that this is better in terms of its language. We think that it is also better in terms of recognising that you are looking at not just an impairment, which is mentioned in the definition, but also the social impact of that. You are recognising that a lot of the disadvantages come

from the way in which society has not recognised and helped people with disability, rather than focusing on what we see as a medical model, which is focusing on the aspect of having a disability.

There are two aspects of the Equality Act that we felt should not be brought over. This is to do with regulations that look at excluding aspects of disabilities that focus on impairments that might stem from an addiction or those who might exhibit certain kinds of behaviour. We felt that that was not appropriate when thinking about the definition of disabled children, particularly when thinking about aspects of children who might have disabilities from foetal alcohol syndrome or addictions that have come across from that earlier life experience. It is also about recognising that, for some children with disabilities, particularly those with neurodivergence, sometimes that might exhibit in a way that might seem to fit into definitions of unacceptable behaviour. We felt that that also should not be something that is part of the definition, to recognise that aspect of disability as well.

Chair: To help the committee, do you have something that you can provide for us, as it were, so a template expressing the very things that you have just described?

Alex Ruck Keene: There is the definition that is included in the recommendations.

Professor Alison Young: Our report sets this out quite clearly for you, so that provides an account both in the summary of our report and in our full report.

Chair: You would not add to that. You are happy with that as it stands.

Professor Alison Young: We are happy with that, yes.

Alex Ruck Keene: Do you mind if I make one very quick observation? The context in which you are now reporting is not the context in which the Law Commission reported.

Chair: That is why I am asking you whether there is something you need to add to this in this new context.

Alex Ruck Keene: Because we have the independent review of prevalence of mental health conditions, ADHD and autism, we have a social context within which it is very clear, and was very clear when I was on the review—I am speaking personally—that there is a lot of contest and tension. We have a review that could go one way or another.

Reading between the lines, you can see that some of the thoughts that might be going behind it might be saying, "There is too much of this stuff going on", where there is potentially the entitlement that follows on a definition. My observation is not about the definition, which clearly has to be right, because, unless the Equality Act definition changes, you have to have consistency. It is a very acute awareness of the political and environment within which you are now considering these issues.

Chair: Thank you. That makes sense.

Q38 **Baroness Kennedy of The Shaws:** That is a very interesting thing for us to all have in mind. There has been a shift because of this concern about the great increase in numbers and that background.

I wanted to tease out from you an issue, or it may not be an issue. The Law Commission has recommended the introduction of this comprehensive statutory guidance. Is it going to help protect the human rights that we have just been talking about? What about a separate unified legal framework? That is the great debate in here, is it not? Let us home in on where the debate lies. I wondered what your thinking was on that. Why is there talk of a unified legal framework as distinct from the recommendations that Connor and his colleagues have come up with?

Professor Alison Young: I think that what you are drawing on there is that, as the Law Commission, we have our particular terms of reference. Our terms of reference were looking at social care of disabled children. That puts you in a little bit of a tricky situation in some senses, because we very much felt that there was a need for a distinct framework for looking at the care of disabled children. Originally when we sent out our consultation paper, we felt that a very good way of achieving that would be to have to have a separate statutory framework for disabled children.

Obviously that then raises the issue that a lot of the things that we were thinking about could apply just as equally to children in need as to disabled children in need. If you had a separate distinct framework just for disabled children's social care, the question would then become whether that would give rise to knock-on possible problematic consequences for other children also receiving social care, but who were not disabled.

Because of that, we felt that the best way of trying to think this through was to have a framework for disabled children within the Children Act, rather than taking disabled children out of the Children Act. We would end up with a statutory framework for disabled children within the Children Act, with a set of statutory principles. The guidance provides you a means of building on those statutory principles to give more practical and detailed application of how those principles would apply in practice. Our statutory framework of principles would make sure your decisions that were made would always prioritise the rights of the child but would also think about—

Baroness Kennedy of The Shaws: There would be the additional element of disability.

Professor Alison Young: Yes, exactly. It is about trying to get the two to work together. You have a statutory framework that sets out clear statutory principles and then guidance, which also could be made by consulting with disabled children, local authorities and carers, so you have a really good understanding of how that applies in practice.

Also, the advantage of having guidance in addition to statutory principles is that you are able to produce that guidance in much more accessible means. You can have guidance that is the same guidance that is then produced in an easy-read version or a way that is accessible for children to access. It gives you that ability to have a more detailed understanding of how these principles would apply in practice, but also helps to increase accessibility, so that individuals have that ability to protect their human rights.

Baroness Kennedy of The Shaws: You created a very vivid picture of that whole problem about this mismatching of the different provisions and how difficult it is for families to navigate their way through it. Do you see this as being the real solution?

Professor Alison Young: It is one of the solutions. That is the best way of putting it. We came up with an array of recommendations. One of them, which we think is one way of helping to resolve that problem, is bringing it all together in one place. You often find that, as we said, for individuals, you are more likely to go away and look at the guidance than you are necessarily to look at legislation. To have that element of accessibility and to be able to see those principles gives you that ability to find out what your rights are and to be able to act on them and protect them.

Baroness Kennedy of The Shaws: You said that there is no one textbook and here you are. There is the challenge I am putting to you. At the end of all this, one of you has to write the textbook.

Professor Alison Young: I might defer to these two experts.

Baroness Kennedy of The Shaws: We need one of them to make it simple for young lawyers coming in who are going to do this work, but also for families who want to be able to access a simple guide as to how they can get rights for their children.

Chair: If you want to take the challenge that has just been given to you by Lady Kennedy, where do we buy the textbook?

Connor Johnston: The challenge has been taken. We said that there was no textbook at the beginning. There is a textbook now.

Baroness Kennedy of The Shaws: Make it smaller, handbag-sized and all of that.

Professor Alison Young: We have the summary.

Connor Johnston: More seriously, it is fair for us to acknowledge that, if we had recommended a separate legal framework, which is what adults have, we probably would end up with a simpler solution that is more accessible. The risk, as Professor Young has identified, is of knock-on unintended consequences. We have to keep in mind that Section 17 of the Children Act is not just about meeting the needs of disabled children.

It is about meeting the needs of children in need more generally, and that can be needs relating to poverty, racism or poor housing.

Our concern, which was put to us by a number of stakeholders, was that, if we separate out the function of meeting needs relating to disability from those other needs, we would make it harder for social workers to view and identify the needs of children holistically. We heard a lot during this review from families who, as a result of their care responsibilities, had lost jobs; some had lost homes. It is those cases where it is vital to be able to look at a child's needs holistically. Our solution is something of a compromise to try to achieve as many of those objectives as possible, including the need for simplicity and a holistic approach.

Alex Ruck Keene: I entirely agree with everything. The only observation I might make is that you might feel that the principles that have been recommended will apply just as much across all children's social care. The Law Commission's terms of reference say, "Look at disabled children's social care". If one was thinking of a midlife upgrade for the Children Act, those principles might be thought to be ones that would apply across the board and might help in terms of some of the embedding of the human rights principles that are driving this committee's interest and work.

Chair: As I understand it, you are not saying to us that it is a choice of either the guidance or the legislation, but that the two together are the best way forward.

Professor Alison Young: That is right.

Q39 **Afzal Khan:** How are the needs of the disabled children, as well as the needs of their parents, carers and siblings, assessed? A supplementary to that is whether this should be reformed.

Professor Alison Young: One difficulty you find in this area is that this is one of those situations in which the duty has come from being read into the legislation. It is an implied duty from the legislation that requires local authorities to assess the social care needs of children in need in their area. This is meant to be on the basis of those who appear to be in need. That is the requirement to look at the children who appear to be in need and to make an assessment. Because it is implied and not spelled out, that means it is not necessarily clear and obvious for parents and carers of disabled children that this is how the assessment process works.

The difficulty you also have, as we have heard from the previous evidence session, is that there are lots of different types of assessment that can be made. They all tend to interlock. That can mean that you end up with an assessment for one aspect that does not necessarily cover all the holistic elements. There can be different routes in and it can be very difficult for you to understand which particular route you need to take to get your assessment. They can overlap with each other, sometimes in a way that might mean parents and children are having to constantly tell the same story to different individuals, which obviously has consequences

for thinking about protection of your right to family life and privacy, because you are constantly having to go over the same information.

Also, in the worst-case scenario, you can have situations where different departments within the same local authority are all trying to see whether you meet the criteria for a particular need. You might end up, in the worst-case scenario, falling through all of the gaps, in a sense, because you do not have that holistic oversight of how it works. Those elements made us think that there is a need to think about reform in this area to make it much clearer where the duty is, what the duty is and how it operates, and, again, for this to be accompanied by guidance to help provide assistance on how best to implement those assessment duties in local authorities.

Afzal Khan: There is no national eligibility criteria for the provision of support to disabled children in the social care system. To what extent does this raise human rights concerns?

Professor Alison Young: As I think was picked up in the previous session, this is an area that we were very much concerned about, because the lack of national eligibility criteria can give rise to unfairness. We have heard about the possibility of a postcode lottery, where you might be eligible for support in one area but not if you happen to move to a different area. We also heard from the previous evidence session that there can be a timing problem. The criteria might mean that you are assessed differently at different times.

We felt that this was very problematic because of the fact that it could give rise to possibilities of unfairness, which obviously then starts to trigger problems with Article 14 of the European convention. You find that disabled children in the same situation are not being treated in the same way because of this potential lottery. My colleagues will have much more information about the evidence we found when we consulted about the impact of this postcode lottery and the lack of national criteria.

Chair: It would be helpful if you could give us one or two examples—not now, but perhaps in writing afterwards—of how that works in practice that we can include in our report. I think that the committee would be very interested in that.

Connor Johnston: To build on the points that Professor Young has made, the concern is discrimination and Article 14. There are three different aspects of it. You have heard one, which is that children with similar needs are treated differently dependent on where they live. We saw that when we looked at the eligibility criteria. We looked at 104 criteria across the country, or we tried to find 104 criteria. We could not find all of them. Of those that we found, no two were the same. That is the first form of differential treatment. Children in the same position are not being treated in the same way.

The second is that we have children as a whole not being treated the same as adults. This postcode lottery is not a new observation we have

come up with. It has been noted since at least 1998 and used to apply to adults as well. That was fixed when the Care Act was brought into force, with accompanying national criteria for adult social care, in 2015, but children have been left behind. We end up with children being treated differently to adults, in the sense that one has a consistent system and the other does not.

The third, which turns on the detail of the eligibility criteria we have looked at, is that children are treated differently dependent on their particular conditions. A common feature of some of the eligibility criteria was that it was harder for people with particular conditions to get support. For example, sometimes ADHD would not be enough. Sometimes autistic children could only get support under the eligibility criteria if they had an additional disability as well. Children are being treated according to diagnosis and label, rather than need.

Afzal Khan: The Law Commission recommends that the national criteria be developed, but it does not say precisely what these criteria should be. Do you have views on what the national eligibility criteria should look like?

Professor Alison Young: This is another one of those areas where it is very difficult for the Law Commission, as an independent law reform body, to explain precisely what we think the criteria should be, because we recognise that a lot of this is going to depend on thinking through what political choices you are going to make about the level of social care you wish to provide, as well as engaging issues of the distribution of support from nationally funded and local-authority-funded pots of money. It is one of those issues where us giving too much detail of what we think the content should be would be problematic in terms of our constitutional role.

We thought long and hard about what we thought the process should be to come up with those criteria. We felt it was very important to make sure that there was this element of communication between national Government and local government to think about how the distribution of money was made. We recognise that it is all very well having criteria, but, if there is not the money and the resources to provide the services, this will fall down and you will not have an ability to actually protect the rights in those circumstances.

We also felt that there should be input from children with disabilities, their families and carers. We felt that that could also be done through groups who represent these interests. We felt that there was a real need for a conversation to be had with all those who have an interest in this particular assessment to think carefully about what those criteria could be. We heard from Mr Ruck Keene earlier about the backdrop of thinking about our understanding of what you mean by autism, for example. It shows that this is quite a difficult issue that needs to be dealt with very carefully to come up with the right criteria and that recognises the need to make sure the resources are there.

Chair: I was hoping that we might hear from Mr Ruck Keene about what the national eligibility criteria might look like, so the floor is yours.

Alex Ruck Keene: In the earlier session you heard that there might be some proposals that could be put for you to think about. They are definitely a very helpful starting point. My main observation is that one real difficulty here is that we have so little data. I was the poor person who had to go through looking at all the different eligibility criteria. I am afraid that I did not manage to get to all 143 authorities. We stopped at 104, when we had reached saturation point, when you realise that we just do not know what is being done.

Linked to that, we also have a very profound problem that we do not have enough data being gathered by local authorities and ICBs about children with disabilities in their area. Then we do not get sufficient oversight of that for monitoring bodies. One real complexity here is that, even before we get into the discussion about what we should be thinking about, even if we are then talking about what the minimum standard is, we are operating in this real morass of a data gap, which is a hugely problematic position to be starting in.

Lots of people have tried doing different bits of work at different times, but the fact is that we have not had that recognition of the importance of data. I am really reminded by Mr Johnston, in one of the bits of the report that he drafted, of that language from Alf Morris MP saying that, if we are doing this stuff without data, we are making policy blind. That was 40 or 50 years ago and we are still doing it. It almost speaks to how low a priority it has been seen as nationally that we are still talking about this in 2025.

Chair: I was serving with Alf Morris in the House of Commons in those days and he was one of the great champions for disabled people. It is slightly depressing to hear these arguments being repeated now in 2025. I know that Dr Swallow has a point of view about this. Can I bring you in on that as a supplementary question?

Q40 **Peter Swallow:** I wanted to touch on that because this is a conversation we are having in the context of the Government looking at the special educational needs and disability system. I do not want to go too far down that rabbit hole, because that is a very serious but different topic in its own right. There is a live conversation ongoing about the role of diagnosis and how diagnosis is often used as a barrier to accessing appropriate support, rather than what it should be, which is something useful in and of itself but not a barrier to accessing the support needed, particularly where identifying that support need is not dependent on a diagnosis. Is that underlying what you are talking about here? Is there too much of a fixation on recording only diagnosed need and not identified need?

Alex Ruck Keene: It might be part of it. If you read the Law Commission report on the data-gathering aspect, it is more a failure to recognise that we need to think carefully about who our disabled children are in each area so that we can then respond.

Part of that is also because the definition of disability in the Children Act is so outdated and does not match the modern definition of disability, in terms of saying that it is not just the impairment but the impact of the impairment. You then have local authorities that are breaking the law but trying to come up with definitions that mesh with a more modern understanding. They get themselves incredibly tangled up in, "Is this about diagnosis? Is this about need?"

Underpinning it all is the difficulty that if you start saying, "You have an individual entitlement to something", and then someone says, "I wish it", that starts costing money. That is at the heart of one issue underpinning the SEND crisis, which I appreciate you are looking at or thinking about separately. There is the same underpinning aspect that, the second you say, "This matters. You have an individual right to something", you have to have something that enables you as a gateway. If you have very stretched resources—the metaphor is not going to work—the gateway starts getting turned into a barrier. Then you get the fight over the diagnosis and the whole thing becomes immensely problematic.

One observation I would make is that not quite buried in the Law Commission report but sitting there perhaps not with huge priority is one recommendation that there should be a power to meet the social care needs of disabled children. That gets around the fact that you might have a situation where someone is waiting for the autism diagnosis for three years but it is obvious that they have needs. That is to help circumvent some of the problems that arise otherwise.

Chair: I am going to bring in Baroness Kennedy, but before doing so, to reinforce what you have just said, Alf Morris always insisted that, if you did not collect the data—and that that might suit some people—you could not possibly know what the answers are to the questions. The two run hand in hand. I have certainly been very taken by what you have just said.

Q41 **Baroness Kennedy of The Shaws:** One of you will have a view on this, but you know that there are concerns expressed about deprivation of liberty orders and how they are used. This relates, as you might imagine, to Article 5 of the European Convention on Human Rights, which protects the right to liberty and security of everybody. Are there concerns that you have come across or that you have had about the ways in which deprivation of liberty orders can operate?

Professor Alison Young: This is a question for Mr Ruck Keene, because this was not within the scope of our report. The Law Commission had reported on the mental capacity and deprivation of liberty earlier, which Mr Ruck Keene was also involved in. We are very grateful for his expertise, so I will defer to his expertise.

Baroness Kennedy of The Shaws: I was eyeballing Alex.

Professor Alison Young: That is very wise.

Baroness Kennedy of The Shaws: I know of his great experience.

Chair: It is like a hospital pass. It is over to you.

Alex Ruck Keene: There are three issues. One is the very definition of deprivation of liberty. In a way, you cannot go there because that issue is before the Supreme Court at the moment. I will also declare that I am involved in that case, but you cannot go there for constitutional reasons.

Baroness Kennedy of The Shaws: We know that you are the man.

Alex Ruck Keene: There is the very definition of deprivation of liberty and how one thinks about whether that applies differently to adults and children. There is that definitional issue.

Then there is the procedural issue, which is how we are authorising all these things. In the adult context, we have DoLS. We understand now that we will probably have liberty protection safeguards hitting from 16-plus. We are currently grappling with deprivation of liberty orders before the High Court and the inherent jurisdiction. Government are very keen, in the Children's Wellbeing and Schools Bill, to have a framework to have relevant places and deprivation of liberty. There will still be court orders. There is definitely stuff that can be done in terms of authorising, but the honest answer is that neither the first nor the second are really the issue.

The real issue is why we are getting to the situation where we have people identified where the only thing we can offer is something that is a deprivation of liberty. I should say that it is to the credit of DfE that, alongside the Children's Wellbeing and Schools Bill, it has commissioned work thinking about the task and finish group, addressing the need of children in complex situations giving rise to deprivation of liberty and all those things where you see all the things that have happened. In a way, it is incredibly apt that this inquiry is being held today if you think about human rights starting in the small places close to home.

Baroness Kennedy of The Shaws: That is Eleanor Roosevelt's inspiration, yes.

Alex Ruck Keene: It is such a powerful thing. In the context of the social care review, the commission definitely saw that you get situations where, if there had been an earlier intervention, the situation would not have escalated. It is not so much the person with the very profound physical disabilities. It is the person with the complex mental health condition or the person with autism and a complex social situation. No one knows who they are. Are they social care? Are they healthcare? The person gets bounced between the two. It gets worse and worse and then the only thing on offer is something unfeasibly draconian.

I know that the primary focus of this committee is thinking about the ECHR, but, for this perspective, if you think about Article 19 of the Convention on the Rights of Persons with Disabilities, the right to live independently in the community applies just as much to children. There is also the right to family life and living with families. If one prioritises and orients around that, you do not get to these situations. I would also say,

from a pure pounds, shillings and pence perspective, that it is almost invariably much cheaper to do that.

Baroness Kennedy of The Shaws: It is much cheaper if you get in there early. It is about nipping things in the bud earlier on and having proper resolution of problems at an earlier stage. I agree.

Q42 **Peter Swallow:** When I was a teacher, we used to talk a lot about the voice of the child, which is something I always championed. I observe that, as is always the case, it is those children who are most able to use their voice and advocate for themselves who are most likely to be heard. When we look at children interacting with the social care system, it is often the children least able to advocate for themselves who we are talking about, particularly when we are dealing with disabled children.

The right for disabled children, and for all children, to have their views heard is protected under Article 12 of the UN Convention on the Rights of the Child. Do you feel that there is sufficient ability for young people themselves to voice their views in the current system? If not, what can we do to strengthen that?

Professor Alison Young: There are some ways of trying to incorporate this, but, as with most things, it is not necessarily fully clear. Because that lack of clarity as to when you have the right to advocacy and what it attaches to in particular is the difficulty, that might mean that, in practice, you do not necessarily get the right when you need it.

One thing that we looked at was that one of the principles we had in our statutory framework was making sure that decisions were not just prioritising the rights of the child but also allowing the child to have the right to make those representations, and coupling that with clarity of a right to independent advocacy for children when it comes to the element of assessing their needs and participating in that decision-making process of what those needs would be and how best to meet them. We hope that that way would give you that practical shoring up to make sure that advocacy and the rights of the child were actually taken into account fully.

Connor Johnston: There is a further practical recommendation we make that I think will help with this. That is that those carrying out the assessments of social care needs of disabled children should have appropriate expertise. One thing that we heard was that those who carry out the assessments, for example, might not know about disability generally or specific disabilities. The manifestations of that might be an assessor who does not have the means to communicate with a child who is non-verbal. We have specifically recommended that assessors should have appropriate expertise and training, which we see as a potential fix to that.

Peter Swallow: Does that specifically include expertise and training in how to capture the voice of that child?

Connor Johnston: The recommendation does not go so far. It is a more general recommendation that they should have appropriate expertise, which I would have interpreted in that situation as being exactly that.

Peter Swallow: Do disabled children and their parents or carers have effective means to raise complaints and receive remedies? I hear, as a constituency MP, all the time how challenging it can be for parents, carers and young people themselves who feel that the system is not working to support them. I hear how difficult it can feel for them to raise their concerns. Is the current system doing enough to capture and address those concerns?

Professor Alison Young: We found the same evidence. It was very difficult, because of the elements of the range of remedies and the difficulties of perhaps getting access to those particular remedies, so thinking about "Which one do I take first?" and how much time it might take to go through an internal complaint and then the ombudsman. You have the backdrop of the SEND, but the difficulty with SEND is that it is only with regard to educational needs. That will mean that for some disabled children you have a SEND route, but for others you do not. That can cause another extra layer of confusion as to what the appropriate remedy might be. We also heard issues about difficulties of access to judicial review for those who do not have legal aid.

We had the same element of hearing from people that it is not always easy to know what your remedy is and how to get hold of it. This is why we recommended that there should be a system of effective remedies that was fair, accessible, independent and provided this effective means of resolving disputes.

Alex Ruck Keene: This is not a theme that is unfamiliar to this committee and it is a perennial problem. I found it very striking, because I did quite a lot of the work thinking about the remedies side. Nobody seemed very satisfied. This is not a situation where, for instance, local authorities are saying, "This is all fine", and it is just parents who are complaining. Everybody seemed to find this unsatisfactory. Within the Law Commission terms of reference and the extent to which the Law Commission could go away just on that project and say, "By the way, judicial review needs to be more accessible for everybody", that runs into a governance problem.

It starts making rights completely empty. If you have an entitlement to something and you do not have an effective ability to do something about it, that is where the CRPD comes in. Your right to it is completely non-existent.

Chair: If we can move on from the situation—some of it is good, some of it is bad and there are things that will need to change—two of my colleagues have questions to you about the way forward and the methodology for change.

Q43 **Baroness Lawrence of Clarendon:** My question is around proposals for

change. If accepted, many of the Law Commission proposals might take years to implement. In the short term, what can be done to improve human rights protection for disabled children?

Professor Alison Young: You are right. This is one of the downsides of being able to review everything. You can come up with lots of solutions but they are not necessarily easy to implement quickly, so it is good to ask us to think about what things might be done more quickly than changing the law.

There are some elements of clarity that can be done quite quickly. We heard earlier from Mr Ruck Keene about the confusion that you might have about whether something is part of your Section 17 duty or of early care assessments or family health assessments. Clarity on those elements could be done quite quickly to clarify to local authorities how they fit in with their Section 17 duties and maybe make that a little clearer. That could provide one thing that could be done more quickly.

We heard in the previous evidence session as well about the importance of training, which could be done much more quickly than trying to bring in changes to the law. We also heard in the previous session about the roles of disability and social care officers in local authorities who can perhaps co-ordinate different types of services. Again, that might be something that could be done more quickly to help get that cohesion across different departments and make things more effective to implement and give more joined-up thinking about social care.

The idea of guidance is quicker to bring in than legislation. Although we have recommended a new statutory framework and guidance, guidance could be brought in more quickly to clarify some of these areas and make things more accessible than waiting for legislation.

Q44 **Lord Murray of Blidworth:** Before I ask my question, I should declare an interest. I am, of course, in chambers with Mr Ruck Keene and Professor Young at 39 Essex Chambers.

Could I just ask you a very open-ended question, which I hope will round off the session? Do you have any further human rights concerns related to the disabled children's social care system in England that you would like to flag and that we have not already discussed? Are there any other recommendations that have occurred to you, possibly in the course of the session and, indeed, previously, and that you would wish us to take forward?

Professor Alison Young: As the Law Commissioner, I am going to rest on the recommendations in our reports, on which I was wonderfully aided by my two colleagues. I will hand over to my colleague in chambers, Mr Ruck Keene, who will be able to go further than that.

Alex Ruck Keene: It is such an important question to ask because, to my mind, it is about being clear about the environment within which we are operating. We have the environment that we just talked about in terms of the prevalence review. We also have the Mental Health Bill,

which is just about to get Royal Assent. That is going to have significant changes to how one thinks about mental health care in relation to all people.

If we have an increased threshold for detention under the Mental Health Act, and we are not going to have learning disability and autism in there for Section 3 for the longer term, it is about how that then tracks through to making sure that social care is—I do not want to say "picking up the pieces", because that is completely the wrong way round—starting upstream and, wherever possible, ensuring that people's needs are met, so that that is not potentially giving rise to mental health crises, and then to problems with a Mental Health Act that is changing for different reasons. That aspect is hugely important.

One of the challenges—it is almost probably an insoluble one—is how you get integration between health and social care, which is one of the things that is most important in the context of children. That is not just mental health care but physical health care. If the two systems are always going to be funded differently, by the local authority for social care and by central Government for the NHS, we need to make sure that that is glued together in a way that does not give rise to problems. The Law Commission tried to make some important recommendations within its wheelhouse.

I raise this very cautiously, but we do have a Private Member's Bill before Parliament—the Terminally Adults (End of Life) Bill. We have a cohort of people who will be coming out of childhood with disabilities. We will have a realm within which, for instance, there will be a greater suggestion that, if you listen to the voice of the child, you get greater participation and greater reliance on decision-making, and then you might have a zone in which people are saying, "That former child and now adult is now in a position where they are thinking about asking for assistance".

I am not making any points there in terms of arguing for or against. I am just trying to flag that it is about thinking about how all of this is landing in a wider context. In the context of terminally ill adults, you will be aware that the Children's Commissioner is making observations in relation to childhood running, to some extent, beyond the age of 18.

I am absolutely not speaking here on behalf of the Law Commission. That really is a personal view. I am just trying to get across that one of the real advantages of this committee is that you can think across the piece, and think about the piece human rights-wise. Social care is such an important part for disabled children, but it sits within a wider context.

Chair: Thank you very much. You are right, and we do think across the piece. We are looking at any number of complex issues that have human rights dimensions.

For today, I would like to thank Professor Young, Mr Ruck Keene and Mr Johnston for coming and sharing your extraordinary experience and valuable knowledge on this hugely important issue that affects so many

people in very direct and personal ways. Those who have either joined us online or been here in the committee will realise how seriously we are taking this question and that we will be working on our recommendations in the period after Christmas and the new year with some further sessions to come with oral evidence. We have also received a lot of written evidence, which is now on our website too.

Thank you very much, all of you, for being here today. For those who have followed our proceedings, we will be sitting again next Wednesday, when we will be continuing our inquiry into AI, or artificial intelligence, and human rights, just to Mr Ruck Keene's point that we think broadly and widely, and universally. I hope that some of you who have been with us today will join us again then, but, with those words, I close today's proceedings.