



HOUSES OF PARLIAMENT

## Joint Committee on Human Rights

Oral evidence: [Protecting human rights in care settings](#), HC 714

Wednesday 8 March 2022

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Members present: Harriet Harman MP (The Chair); Lord Brabazon of Tara; Joanna Cherry MP; Lord Dubs; Florence Eshalomi MP; Lord Henley; Baroness Ludford; Baroness Massey of Darwen; Angela Richardson MP; David Simmonds MP; Lord Singh of Wimbledon.

Questions 30 - 36

### Witnesses

[I](#): Professor Wayne Martin, Principal Investigator, Essex Autonomy Project; Sanchita Hosali, CEO, British Institute of Human Rights; Kari Gerstheimer, Founder and CEO, Access Social Care.

## Examination of witnesses

Professor Wayne Martin, Sanchita Hosali and Kari Gerstheimer.

**Q30 The Chair:** Welcome to this afternoon's session of the Joint Committee on Human Rights. This is the third evidence session of our inquiry into protecting human rights in care settings. We have already done a substantial amount of work on the issue of human rights in care homes, issued two reports, had correspondence with Ministers, and proposed a new set of regulations to put the human rights of those in care homes into law. In our previous two sessions of this inquiry we heard evidence on capacity and mental health. Today's session will focus on matters related to autonomy, decision-making and enforcement of human rights. Of the Joint Committee on Human Rights, half are members of the House of Lords and half are the House of Commons, and obviously our concern is human rights, as our name suggests.

We have two panels of witnesses to give evidence to us today and I am very grateful to them for joining us. Our first panel are experts on personal autonomy and human rights. We have with us: Wayne Martin, the principal investigator at the Essex Autonomy Project, who researches projects and leads in the delivery of workforce training—welcome, Wayne, and thank you for being with us here today; Sanchita Hosali, chief executive officer of the British Institute of Human Rights—thank you for joining us, Sanchita; and Kari Gerstheimer, who is the founder and chief executive of Access Social Care, which provides free legal advice to people with social care needs. Sanchita and Kari are with us remotely. I will introduce our second panel when we come to that, but they are representatives of care providers in the private and not-for-profit sectors. We are looking forward to hearing from them too.

Perhaps I could kick off the evidence from our first panel with a question to Wayne Martin. Article 8 of the European Convention on Human Rights protects the right to private life and the right to family life. Often people are unaware that the European convention not only deals with issues of the right to a fair trial and the right not to be detained without due cause, but goes as far as protecting the right to private life and the right to family life.

The notion of personal autonomy is an underlying principle of the interpretation of Article 8. Bearing in mind that you are an expert on this—there are many experts out and about, but a lot of people are not expert on this—can you explain with as little jargon as possible how personal autonomy is defined and how the principle applies to individuals in care? In particular, should there be a specific legislative or regulatory framework to ensure respect for personal autonomy in care settings?

**Professor Wayne Martin:** Thank you for the invitation to appear before this committee. It is worth recalling that the notion of autonomy is first and foremost a political notion. It is what Ukrainians are fighting for right now; the right to set their own laws—auto nomos—and, correlatively, to be free from domination by people on them.

Your question was about personal autonomy. Political autonomy is an ancient notion; personal autonomy is a more modern ideal. There are lots of theories out there, and I will not trouble you with them, but if one was going to encapsulate it, the idea of personal autonomy could be summed up as the ability to lead one's own life by one's own lights, by one's own values, and in accordance with one's own will. That is a profoundly important principle in our political arrangements and, as you say, it is an animating principle of all human rights standards in the modern world.

First, I would urge the committee to keep in mind three points in thinking about how this ideal of personal autonomy applies in care settings. My first keyword is what I call *automania*. Personal autonomy is profoundly important and it is very regularly under threat. We should value it and human rights standards protect it. That sometimes leads people to think that it is the only important thing, or that we should have no compromise on autonomy, or we should maximise autonomy in care settings. That is a fallacy. It is important to recognise that autonomy is profoundly important, but other things are also important. Health is important. Dignity is important. Well-being, welfare, is important. A lot of the hard problems in this space involve compromises—weighing up proportional approaches in public policy to ensure that autonomy gets its due, but we also look out for other rights and other values.

The second key word for me is *tragedy*. If one looks to the history of the literature on personal autonomy, it begins in the ancient world and it is regularly a theme in tragedy; Sophocles writing about Antigone's autonomy. If one thinks about it, it is not really surprising that if we decide that as a society we are going to value personal autonomy, and people are going to set their own laws and live by their own lights according to their own will, sometimes there will be unhappy endings. Sometimes that will not go well. If there are no unhappy endings, you are not really valuing autonomy. One of the things one has to think about is how we equip our workforce, who are always inclined towards protection, to make sure that they are protected, and to respect the autonomy of the people in their care.

The final, and in many ways the most concrete, point I would make is about support. Personal autonomy is not something that we can manage by ourselves; we all need help from others in order to do it. People who are in care settings are not, by definition, at the strongest possible configuration of their situation; they are not masters of their situation. We need to make sure that we provide them with the support they need to live their own life by their own lights and according to their own values.

In 2005, Parliament—wisely, I believe—inserted an extra sentence right at the top of the Mental Capacity Act. It was not in the Law Commission's draft Bill. Section 1(3) says that no one shall be found to be lacking in mental capacity “unless all practicable steps have been taken to help him to” make a decision for themselves. That is a beautiful sentence. It is a very important principle. It is the support principle. A few years later, the

UK ratified the UN CRPD—the Convention on the Rights of Persons with Disabilities—which is much more explicit about that obligation. Right now, our research shows that that is something of a dead letter. Very little is happening on the ground in practice to really live up to the commitment that Parliament laid down in the Mental Capacity Act. That is the bad news. The good news is that it is an area to look to for really improving practice on the ground.

**The Chair:** Thank you very much for an excellent introduction to this evidence session. I am grateful to you.

Q31 **David Simmonds:** I am a Conservative member of the committee from the House of Commons. Consultation is enshrined in law and seen as an important part of the process when it comes to the adequate involvement of care users and relatives in decisions that are made. I would like you to outline whether you feel there are particular concerns in respect of people with learning disabilities, autism and, as has been touched on in the previous answer, those who may lack the capacity to make decisions.

**Sanchita Hosali:** That is a really good question, which links very profoundly to the previous question about autonomy. What does it mean, because what does consultation mean, and what does involvement mean? That is one of the practical beauties of Article 8 in the Human Rights Act, the right to private family life, because it recognises that it is not an absolute right. The idea of personal autonomy, the idea that there should be nothing about you without you, is not an absolute; it is a right that can be restricted. It has in it its own practical framework that will support an individual to understand potentially why their rights may have been risked and to support staff who need to make a decision that may well impact on their rights but that might also be about the protection of other rights, as the previous speaker mentioned.

We have this inbuilt framework for lawful, legitimate aim and proportionality to help us make those decisions. There is absolutely a practice gap. We have the legal tools in the Human Rights Act and use that in concert with the other legal frameworks that are available, particularly the Mental Capacity Act, the DoLS that are attached to that, and potentially the liberty protection safeguards, if and when they come in. But, often, those very specific legal frameworks, rather than becoming tools of securing rights, become tools of oppression that restrict people's rights. They become a decision that does to people rather than a decision with people is about ensuring, promoting and upholding their rights, even if those rights sometimes have to be restricted.

There is definitely a practice concern there. It is about people not being involved in decisions that impact their lives, from the really big picture issues of treatment decisions, access to services and the care that they are receiving right through to the everyday decisions. Something that came up quite recently in some of the practical work that we do to support both individuals and service providers was the permission to open a locker to get your own possessions out of it. The assumption is

that, if you have mental capacity issues, you cannot possibly be safe and able to make those decisions for yourself.

There is a particular issue with people who have learning disabilities or autism, and we see it in other areas, such as people who live with dementia. We hear quite frequently about the assumption that they cannot possibly have capacity, or the idea that they just lack capacity. That is where the human rights perspective comes in and says, "Well, no, in the same way that you have Article 8 rights to personal autonomy, so do the people you are supporting here". You cannot just make that assumption. That is not the correct and legal approach, and it gives you a tool to take a step back and re-make that decision. We found that when you explain that and provide the information and the tools directly to staff in those services, they can make those connections and can make good rights-respecting decisions.

We have the legal tools to do it. The issue is about the practice space. I am always astounded by what we see every day at the BIHR, which is that the staff, particularly in health social care, who are responsible for whether an individual's rights are respected or upheld in that service, treatment decision, care, have almost never heard of the Human Rights Act. Yet it is their actions that will determine whether those individuals have their rights upheld. So in our experience it is a significant practice gap, not a legal gap.

**David Simmonds:** That is a really clear steer: that it is not a legal issue but a practice issue.

Q32 **Baroness Massey of Darwen:** My question ties in very nicely with what Sanchita was saying at the end, so I will ask her to come in first on it. It is about something that has come up in the context of this inquiry—training to raise awareness of the importance of human rights and how you implement it in care settings. Sanchita, do you have any thoughts on that? How would you organise training? Who would do it, and how would they do it?

**Sanchita Hosali:** I have many thoughts about that.

**Baroness Massey of Darwen:** Good.

**Sanchita Hosali:** We work with roughly 2,000 to 3,000 people every year to support them to understand the Human Rights Act and to put it into practice. A large percentage are staff working in front-line services, mainly health, social care, social support, social welfare-type settings. I would probably suggest that the question may even need to be stronger, in that it is not necessarily about raising awareness of human rights, because often people have an innate sense of human rights.

It is much more about how you develop that into a practice that is used every day. We see staff having food safety training, fire safety training, safeguarding training, and prescriptions and medicines training. All of those are about whether people's rights are being upheld. What they will not have is the foundational training about the Human Rights Act and

what it means for their day-to-day practice. We often find with the staff we work with that it is the missing puzzle that connects all those disparate, often siloed, things that they are doing. Even fire safety training is about the right to life and ensuring that we are respecting that.

It is very possible to do it. We do it day in and day out. The gap is that it is not seen as the mainstay of healthcare settings. All those other types of training are seen as the requirement, while human rights have become this add on, which they really are not, because we need to understand how the law works, and that it is a foundational law and the lens through which we are supposed to apply all the other statutory frameworks. Human rights have been so neglected for so long that there is now a cost attached to that, because we have to fill the gap that has developed over the last 20 years. It is important to view this as filling a gap that should not have been allowed to develop, as opposed to now doing something additional on human rights.

Also, when we talk about training, it is very much about the use of programmatic approaches and about ongoing development and support in services. It is about your induction when you start and your continuing development as you progress through the organisation. It is about your management structures, your supervision structures. It is about the processes and policies that you put into place. We see great policies all the time, but there is no mention of human rights. How are the staff supposed to know that their job is to uphold human rights? It is completely doable, but it requires effort to invest in work to do that.

**Baroness Massey of Darwen:** How would you do it?

**Sanchita Hosali:** One of the key ways we have done it is through commissioning bodies. Commissioning bodies bring in our services and we develop programmes that are specifically about what the service is doing and what the staff are doing and making it real and relevant. The Human Rights Act can be a brilliant piece of legislation, but it needs to be about the practice. In a care setting we are talking about what full prevention looks like when it comes to human rights. It does not look like strapping people to chairs or raising rails without talking to people and making these connections. It is about that relevance and that reality, but situating it in the legal framework.

The legal framework is so important because it gives staff the reasoning that this is not just a nice thing to do; this is the law, a legal framework, that has set standards and duties that we can use to change our practice. It does require that investment and it does require leadership. We do it at all sorts of levels; we do it through commissioning bodies and through individual services that want to do the right thing and ensure that their staff are doing that. It is a very pocket approach as opposed to an overall approach. An overall approach is absolutely possible; for example, we are doing a piece with NHS England and children's services at the moment, so it is there, but it requires the will.

**Baroness Massey of Darwen:** I wonder if Kari or Wayne have anything

to add to that.

**The Chair:** Wayne, you are involved in training. Would you like to respond?

**Professor Wayne Martin:** Yes. I will just add a few things. I would urge the committee to take a lesson from the European torture convention, which sets up something called an independent mechanism; there is also a UN-level mechanism on that. Some of our colleagues have worked all over the world as part of that mechanism. One needs a mechanism, right? One needs something that mediates between the grand ideals of human rights statutes and the actual practice on the ground. No single mechanism will do the trick, but we need to think about what that mechanism is. Things like the deprivation of liberty safeguards might be one sort of candidate for that.

I also completely agree with Sanchita that training is key here. We did some training webinars during the pandemics for front-line workers, and over half of them reported that they were unclear about what principle they should be applying in deciding whether a particular restriction was lawful. So it was not just about whether it was lawful but about which principle to apply. There is a training gap there.

The identity issue idea is also important. One of the things we try to do in our training exercises is to help people on the front line to think of themselves as human rights workers. They do not typically start at that point; they think of themselves as care providers. But the idea that part of the job is to be a human rights worker is an important part of the values-driven approach to training in this area. There is more to say, but we are at a moment of great opportunity. I like to say that we are at the opportunity phase of the pandemic. The pandemic was crisis management for a long time, but in this particular area there is now a lot of awareness of the human rights vulnerability of residents of care settings. There is political will. We see that in this room, but we also see it at every level. There are audits going on all over the place to think about how to do it better. We have to take maximum advantage of that moment in order to make improvements that are long overdue.

**The Chair:** Of course, the point you are making about political interests and political will was amplified by the fact that in the House of Commons today in Prime Minister's Questions, despite all the huge and justified focus on Ukraine, the right to family life in care homes was raised by a Member of Parliament and answered by the Prime Minister. The spotlight is very much on it at the moment.

**Kari Gerstheimer:** I would like to support what Sanchita said about ongoing training and the need to be working with real-life situations. During the pandemic we supported staff members on the front line on things like how you balance visiting rights with health and safety, for example. Working with people on that real-life situation is important, and that ongoing CPD is critical.

If I may, I would like to go back to the previous question about making informed decisions for people with a learning disability and the involvement of family members. It is really hard to make informed decisions or to be involved in decisions if you do not have all the information that you need. There is a need to recognise that Article 10 kicks in here.

**The Chair:** Just remind everybody what Article 10 is.

**Kari Gerstheimer:** I beg your pardon. It is the right to freedom of information. In the context of care settings, having access to things like your assessment paperwork or your care planning paperwork, or having access to information about proposals to make changes to services, perhaps service closures, is really important. We frequently see that people are not given access to that and struggle even when they are asking for it. That is really important to recognise.

Secondly, in relation to family members, we have seen a tendency in our casework for family members to be excluded from involvement in assessment and decision-making processes. We have a current case involving an individual with a learning disability who is detained in an assessment and treatment unit, and the family have been completely excluded from the discharge planning process. As a result, the providers that have been considered are all very close to the unit and hundreds of miles away from the family. We have another case where family members are being ignored and needs and distressed behaviour are escalating, and the real expertise that sits with the family is just not being utilised.

We would recommend a couple of changes. First, we would really like to see all local authorities being required to have an independent advice and support service that serves people with social care needs and family members. Secondly, in certain circumstances we would really like to see advocacy support being provided both to the individual and to the family members. That, in particular, would be really helpful when we are looking at in-patient unit situations. We know that in those situations there are often significant human rights abuses, and it is particularly important that the role of family members is recognised.

A final change is advocacy for people with a learning disability. There are issues with the way advocacy is commissioned. We often see advocates being put in place too late or not being given enough time to enable meaningful advocacy, so people are not being given enough time to get to know the individual and to understand how they want to express their choices. We would like to see some additional training for advocates, and for commissioners on advocacy, to make sure that advocacy is high-quality.

In training, there is a need to understand the importance of the Care Act provisions in particular. In mental health settings, the advocate will often not have knowledge of the Care Act and the interplay with the Human Rights Act, which is quite an important need when it comes to advocacy.

**The Chair:** Your point about advocacy and information feeds into Wayne's point about needing support. They are part of the support mechanism that enables you to have your autonomy. Thank you very much for those illuminating answers.

Q33 **Joanna Cherry:** I am the SNP Member of Parliament for Edinburgh South West. I want to ask about collecting data in care home settings and whether data could be used more effectively by individual care homes and across the system to enable better human rights protections. If so, what sort of data would you like to see collected? Do you think it should be done individually or aggregated across the system? How might it be published in order to increase the effectiveness of human rights protection and monitoring?

**Kari Gerstheimer:** We have very serious concerns about the failures in data collection. We think that a lot more data is needed on race and on types of disability and, in particular, how that demographic data interrelates with eligibility. Who is having which type of eligibility criteria met and who is being turned down? We suspect that people with certain characteristics are being denied access to certain types of care and support. For example, we think that older people might not be having as much access to their communities as working-age people. We often see people with certain disabilities, such as a learning disability, being put in front of a television and that being deemed to be an adequate and appropriate leisure activity. We would like to see more data on who is being turned down for what sort of need.

We need much more information on unmet need, and we know that increasing numbers of people are having to wait for assessments. Who are they? We need more demographic information. We need more data on advocacy services. I would like to say that we need more information and data from the Legal Aid Agency on how many certificates are being issued for community care cases. We know that there has been a significant reduction in support in this area, so we would like to see more.

When it comes to how the data is displayed, we know that a lot of the data at the moment is not in an accessible format, which seems very relevant in this area. We would like to see it displayed perhaps using dashboards, so that making a comparison is much easier. We would also recommend making the collection and reporting of data on ethnicity and type of disability mandatory for local authorities. We know that the datasets are very incomplete, which makes it difficult. Access Social Care used to be part of the Royal Mencap Society, and when we were still at Mencap we made an FOI data request. The response from local authorities was that their software or technical issues meant that they were not able to collect data that they should be collecting. Again, that really needs looking into.

**Joanna Cherry:** Obviously you are talking about local authority level, but I suppose it would be good to have a national picture of what is going on. Who do you think should be responsible for aggregating the sort of data that we are talking about?

**Kari Gerstheimer:** I would like to see the Department of Health social Care doing more in that space, for sure. As an organisation, we work on data. We have been doing some work on advice demand, and it paints a shocking picture. We can see that many people are going without the social care they need. We can see that the numbers of carers calling helplines has risen by nearly 400% in the last two years, because the needs of the people they are supporting are not being met. We would like to see more work in that area. The other body that could be looking at and analysing data is the CQC. We could definitely ask the CQC whether it could make it part of its inspection regime to see whether data is being collected in an appropriate way.

**The Chair:** You talked about the example of watching television and that not meeting needs. What would the data look like that would capture the human rights point that we are trying to look at?

**Kari Gerstheimer:** We would like to see more data on the type of disability that a person has and which of the eligibility criteria in the Care Act they are deemed to have an eligible need under. How is that need being met, and is it being met? We need more data on that.

**The Chair:** That is the background, but what might the bit of data collected that captured the issue about watching television look like?

**Kari Gerstheimer:** In the Care Act there are eligibility criteria with regard to managing and maintaining nutrition and accessing the local community for leisure activities. If we could collect data on the type of disability and the eligible needs that an individual has been deemed to have, that would be a really good starting point. If everybody, or very low numbers, with a learning disability was deemed to have no eligible needs in relation to accessing the community, that would tell us something quite significant.

**Joanna Cherry:** If data was collected about people's eligible needs, would you not also need the care plan that had been devised for them and how it was filled in? Presumably—I say presumably, but tell me if I am wrong—there will be a care plan saying that Jane should have so many hours per week or per day of leisure activity in the community, a care worker will fill in what Jane was doing during those hours, and it will presumably say something like watching telly when it should really be saying something like going for a walk in the park or going to the community centre or something. Presumably the data would need to capture not just the assessment of needs and the care plan but the actual schedule of activities being done with the individual concerned.

**Kari Gerstheimer:** It would be incredible if we could get that level of data. Maybe because the datasets are so poor at the moment, our expectations are set low, but, in theory, yes, it would be brilliant to have that data.

**Joanna Cherry:** We all know that the care sector is already pretty pressed, and that care workers, who are badly paid as it is and

undervalued by society, are very pressed. Presumably this information would have to be collected further up the line. Also, might it be possible to collect a cross-section of data rather than everybody's data, just to make it more doable?

**Kari Gerstheimer:** Definitely.

**Joanna Cherry:** Yes. Okay.

**The Chair:** I am still struggling to work out, as an MP or a member of the public wanting to look at this data, what the data would look like on a piece of paper, and whether it could be collected to give you a broad picture by home, by local authority or nationally, using the TV example.

**Kari Gerstheimer:** The bigger point—just to step away from the television example, because that is very specific—is that we need to know more about who is having which eligible needs identified and which eligible needs are being met. Are we seeing lots of people with a learning disability being determined to have no particular eligible needs, such as in managing and maintaining relationships, or are we seeing lots of people with a learning disability having a lack of eligible needs identified on accessing their community? If we go to that level, it should tell us, or indicate to us, that there may be discrimination issues. Does that make sense?

**The Chair:** That makes more than enough sense. Does it to you, Joanna?

**Joanna Cherry:** It does. Presumably you collect the data, which then has to be subject to analysis, because MPs or ordinary punters will not really understand it without somebody, whether it is the CQC, the Department of Health social Care or a third sector organisation like yours or like Sanchita's, analysing it and saying, "We've looked at the data that's been collected and it seems to us that the human rights of people with a learning disability or people with dementia are not being met in this respect".

**The Chair:** The thing about data, for example on visits, is that we, as MPs, would not need anybody to analyse it; we would just see whether the number of visits by relatives had gone down or whether, in some homes, there was a great number of visits and, in others, they had not recommenced. But, anyway, Wayne will illuminate us further.

**Professor Wayne Martin:** I would focus on cases where the data is already there but is not being shared very well. I have in mind as the consumers of this data not so much Parliament but other practitioners. One thing the committee might consider endorsing is rolling out the NHS digital toolkit to care homes. I hear that a lot from clinical directors, care home managers and care homes. There is a lot of information out there; they just do not have ready access to it.

**The Chair:** Can you just remind everybody what the NHS digital toolkit is?

**Professor Wayne Martin:** I can provide a detailed description to the committee, but it is information that is held in NHS institutions. I talked about a moment of opportunity. We are also in a moment of opportunity where we are really setting about integrating healthcare social care. CCGs—clinical commissioning groups—are giving way to integrated care services, so it is a great moment to be making sure that the data that is out there in NHS records is shared with people who are caring for people in residential care facilities. A particular example is advanced care planning. One way to exercise my personal autonomy when I have dementia is to make plans now about what I want to happen, to get some support to put a care plan together for that situation. It is all well and good to put it together, but if nobody knows that I have it or what it says, it does no good on the ground. That is the kind of information that could be better integrated into the system.

Another example is DNACPR—do not attempt cardiopulmonary resuscitation—decisions. Our written evidence to the committee outlined some of the data that we have gathered on that, but it is hard to know whether a particular DNACPR decision has been challenged. A lot of the professionals we talked to see one of these forms, it does not look right to them and there has not been the right sort of consultation, but how do they make sure that it is known that this has been challenged? Somebody in the system already knows this stuff, but there needs to be a way of sharing it.

I would emphasise a lesson that we can take here from our friends across the Irish Sea. In the Republic of Ireland there is a new institution called the Office of Decision Support and a director of decision-making support. One of the things that the committee might contemplate is whether we need something akin to that here in the UK. It would need to be devolved; you would need to have a different one for each nation, because provisions are different in each of the nations of the UK.

My initial response to your query was about the importance of support for exercising personal autonomy. Right now, very little is happening, or at least if it is happening we do not know about it. The Irish have a person and an office that is gathering information about that and disseminating practice. That is a way of professionalising decision-making support in the way that speech and language therapy is already professionalised in care settings. So that is another area where there is an opportunity for a win by getting people to share their data about what is happening to deliver on the promise of MCA 1(3).

**Joanna Cherry:** It is great to have a positive suggestion like that that we can think about whether to recommend. Sanchita, would you like to add anything to this issue of data collection—how we collect it, how we aggregate it and how we publish it?

**Sanchita Hosali:** Yes. In my former academic life I used to work on a human rights measurement framework, so I feel as though this is a very large discussion. I completely appreciate what the Chair is saying about what that actually looks like and how we make those judgments, because

some data, such as on visiting, is just cold, hard statistics. We can see that visits have gone down and therefore that there must be an issue, but what are we looking at? There is also the quality of the decision and the support that is put in place, and we measure that in terms of human rights. Ultimately, we are probably not the people who need to have the most say in that decision.

We try to champion a human rights-based approach to human rights work. We would say that it is individuals who are receiving that care and who need that care and support every day to live an equal, dignified life. They are the ones who can tell us what good and bad look like in terms of human rights protection. Whenever we think about data, it becomes this big beast in and of itself that we are trying to use in order to support people, but which often excludes them and becomes this professionalised subset that does not have their voices feeding into it.

Any recommendations about data and what we need in order to collect and develop it has to be informed by people's lived experience of what good practice in upholding their human rights does and does not look like. That would be my key input on the data piece.

What I would also say, with a slight level of hesitation, having been involved in a significant amount of NHS and Department of Health social Care working groups on data collection across lots of different areas, is that it is always interesting to me that, when we develop those approaches to data, there is suddenly the resource to support that data, but the resource does not exist to do the human rights practice on the ground. It should not be an either/or, but, often, whatever the new thing is that we are going to do, it becomes prioritised and we do not get the same level of resourcing to support the practical doing of human rights.

Joanna, you mentioned care planning and the assumption that the care plans are in place, but that comes right back down to the service level and what are we doing to have human rights-based approaches, because human rights-based care planning is possible, and we see that with the organisations that we work with. If we are embedding it right at the start and getting some level of actual general standardised approach to supporting people's human rights at those very everyday levels, that should make the data piece much easier.

**Joanna Cherry:** That is very helpful, thank you.

Q34 **Baroness Ludford:** I am a Liberal Democrat Member of the House of Lords. I am turning now to enforcement of human rights, because for human rights to be effective they must, of course, be enforceable. What obstacles are faced by people in care in the enforcement of their rights and in seeking redress?

**Kari Gerstheimer:** First, knowing that your rights have been abused is quite a big issue for a lot of the people we work with. People tend to trust public bodies, social workers, providers, and assume that they have a duty of care towards them. So identifying that there has been abuse of a

right is the first issue. Even if you know your rights, it becomes extremely difficult to seek advice. Citizens advice tends not to advise on community care, and other helplines can have quite limited expertise in this area.

There is a shortage of community care legal aid providers, so legal aid rates are not sufficient, which makes it very hard to recruit and retain legal aid practitioners in this area. We know, because we have just done a project on it, that a fixed fee scheme does not work for this area of the law. Many of the cases we work on are front loaded, time sensitive and complex, and the legal aid system for community care needs an overhaul so that there is greater emphasis on early legal help. To give you a bit of a picture, we work in the early legal help space, so up to and including a letter before action, and we have a 98% success rate with our cases. There needs to be a lot more emphasis on that early legal help space.

It can be quite an opaque system. Cases will often settle in advance of going to court, so there is quite limited case law in this area. In some cases, sadly, that can be quite cynical. Local authorities hope that people will drop off and give up, so they will hold on up to the moment at which you are about to issue in court.

The complaints system and the ombudsman, in many of the cases we work on, are just too slow. Often there is a safeguarding issue that needs to be resolved, or some other urgency, so it would be inappropriate to wait for the complaint system or the ombudsman system to play out. People are left with judicial review as the only option, but, as I have just described, there are lots of problems with judicial review and accessing a lawyer and accessing justice.

We also have serious concerns about the Government's proposals on judicial review and human rights reforms that will make it even more difficult for claimants. I would highlight in particular the requirement to prove a substantive disadvantage to make a claim, and the conduct of the claimant being considered when deciding what a successful claimant should get as a remedy. Those two are of particular concern to us.

**Sanchita Hosali:** Picking up on Kari's last points, you mentioned in your questions that you are concerned about people with learning disabilities or autistic people, and the idea that behaviour has the potential to be damaging in this context. You will know from your previous inquiries that very often when people are in care settings where they should be being supported, those settings are incredibly restrictive and they end up showing distressing behaviour which is then interpreted as challenging behaviour. We consistently see reprimands, actions, sometimes even the police called, because of a person's response to a restrictive, sometimes unlawful, situation in a care setting. All of that can become a perfect storm if behaviour becomes a key element of whether you are able to get a human rights remedy.

I also want to reinforce what Kari said about a digital review. With regard to the enforcement of human rights, the number of individuals who get to court on these issues is the absolute tip of the iceberg. If we focus only

on court enforcement, we are missing all the people who do not get to that point, as Kari mentioned, because there are obstacles, because things get settled, because there are all sorts of reasons why that happens. I would also really encourage the committee, when thinking about the enforcement of human rights, to think about the non-litigation routes in the practice space that are supported.

I want to share a learning from the pandemic, which is that the Coronavirus Act, for all its faults as a piece of human rights legislation, had a specific part which noted that the easements to care provisions could not be applied in a way that was not human rights compliant. Within the week we had social service departments, care providers, hospitals, on the phone to us trying to secure training, because they did not know what that meant. That process of having human rights compliance in Bills leads to those who are bound by human rights law being confronted head on with their duty to put the support in place that needs to be there to prevent the human rights abuses in the first place.

**Q35 Lord Henley:** Good afternoon. I am a Conservative Member of the House of Lords. Kari mentioned the Care Quality Commission, particularly in relation to their role in data collection. The obvious question is: just how good is any of the data that it collects and makes use of? One needs to consider whether that data might be subject to manipulation by those who provide it. Just how effective is the CQC in inspiring confidence that it can protect human rights and guarantee their enforcement in care settings? Kari, you raised the CQC first, so would you like to start?

**Kari Gerstheimer:** In relation to CQC, there is certainly a variety in the quality of inspections. I would also like to highlight that currently inspectors are powerless in relation to commissioning. I will highlight one example of the variety in quality. You will be familiar with the sad case of Rachel Johnson, who died in a care setting. That care setting was inspected as being good, but the subsequent inquest uncovered significant failings which the CQC should have picked up, including basic recordkeeping. The CQC attended that inquest as an interested party. That rarely happens and they only attended on the request of the family's legal representative.

One recommendation we would make is that the CQC should be given leader reports, and it should be mandatory for them to attend inquests where an individual has died in a care setting. Deborah Ivanova has recently been appointed to the CQC, with responsibility for learning disability and autism. Because she is so recently appointed, it would be good to monitor the impact of that new role in relation to people with a learning disability and autism.

Finally, going back to the commissioning point, we are concerned that too much care is currently being commissioned purely on price and that there is not enough consideration of human rights duties. It would be fantastic to see greater use of the inspectorate on commissioning, including being able to assess the effectiveness of provider collaboratives. Provider collaboratives include private hospitals such as St Andrew's, Cygnet,

Priory and Elysium, which run many of the assessment and treatment units where we know that plenty of human rights abuses are taking place. These provider collaboratives have the power to commission services but often do not exercise that power, which means that people are not being discharged from inappropriate settings that themselves have often failed the CQC inspection. I am sure that others would like to add more, but those are the main points that I wanted to bring out.

**The Chair:** Can I just refer back to Sanchita's mention of the importance of human rights being in the regulations and drawing people's attention to them? Are there standard clauses in commissioning for these sorts of services to put the requirement to respect, enforce and report on human rights into the commissioning contract?

**Sanchita Hosali:** Kari, obviously jump in if you wish. In my understanding and experience, and certainly in the commissioning agreements that we have seen, there is usually a long list of laws which you are required to comply with as part of your commissioning contract, and it is often just a list. It just says to comply with the Human Rights Act, the quality Act, and a range of other Acts. That is not sufficient. That is not telling those providers that they have a specific legal duty to uphold human rights. Even if we are talking about private providers, the expectation of the commissioning agreement is that the commissioner expects them to abide by the upholding of human rights. It is often in the list of things that are never checked and never monitored. It is more than it being in the commissioning contract itself; it is much more about how commissioning happens. How are the commissioners understanding the need that they are commissioning for?

A human rights approach would say, "You need to speak to the people who use and rely on those services to help you to identify that need". We almost never see that. When the commissioning process and the tenders are put out, there have to be specific questions: "How do you ensure that you uphold people's human rights?" Be detailed about what you mean by those rights. It does not have to be an entire exercise on the Human Rights Act, but you could certainly talk about Article 8, which we are talking about today, and give examples of that, and think about what that commissioning looks like, for the individuals who are receiving that service and for the staff relationships. Joanna mentioned the staff and workforce issues; rights apply both to the people receiving services and to those delivering them.

Then there are the monitoring processes. What is the expectation on that provider? If they know that the commissioner will ask them specific questions about their human rights compliance, that again is a driver for change. The CQC absolutely has a role in this, and it could do significantly more to be explicit about human rights as the underpinning value base of regulation. There is huge untapped potential to think about what commissioning can do to ensure that human rights are upheld.

**The Chair:** I can see that just referring to Acts of Parliament does not get you near to putting an obligation in a specific way. I would be quite

interested to see a model clause in commissioning contracts in these circumstances that could amplify the rights that are expected to be respected by the people who are providing the services that are being commissioned. If anybody wants to respond to that after this session and draft up something that they would like to see in the contract, that would give the CQC something much more specific to look at to see whether what is being done is human rights compliant in a very specific way. Sorry, Lord Henley, I butted in on your question.

**Lord Henley:** No, not at all. I do not know whether Wayne wants to add anything more on whether the CQC inspires confidence.

**Professor Wayne Martin:** My expertise on the CQC is limited. There are just two points I want to make on what I hear from the people we work directly with. One is that there is often disappointment about what the CQC can and cannot do. Families often think of the CQC as a place they can go to to get something done about a particular complaint about the service they are being afforded, and they are uniformly disappointed to find that it does not serve that function; it is not really designed to.

This is an area where there are discrete human rights problems. There are some bad actors out there: Winterbourne View, for example, or the financial frauds that are perpetrated on care recipients. One needs policing functions with investigative powers in order to set that sort of thing right. This is an area where a lot of the human rights problems involve well-intentioned people trying to do the right thing but maybe being overprotective: "I'm going to lock you in your room. because that's the way to keep you safe". For that, the most effective tool is local champions, having somebody there on the ground—the sort of person who might be a champion for infection control in a hospital. You need a human rights champion embedded in the team. We need to think about that, and but the CQC is not well set up to serve that kind of function.

Q36 **Lord Brabazon of Tara:** I am a Conservative Member of the House of Lords. My question concerns those who pay for care themselves, ie the private sector. How does the Human Rights Act apply to them? Are there different mechanisms for such individuals to enforce their rights, as compared to those available to those who are state-funded? Sanchita, I think you mentioned the private sector.

**Sanchita Hosali:** That is a matter that I have been working on for at least 15 years. There is definitely a difference of approach, and whether it is the Human Rights Act or other human rights law, part of that comes down to the relationship between the individual and the public power or the state at a very basic level. We have a slightly grey area where there is provision of care that is privately paid for—or privately contracted, because technically it is a private contract.

Where does human rights law sit in this sphere? The Human Rights Act has been really good at having a flexible definition of public authorities that changes with our time as we develop. The JCHR, I think, reported on this years ago when the Human Rights Act was in its infancy, talking

about how that flexibility is so important because it recognises the increasingly private nature of the provision of services in the UK. Lots has been done to close that gap in the payment or part-assessment arrangement.

There are different routes to potentially being able to make a human rights claim, even for people who are privately paying. If it is an exclusively private relationship, using the Human Rights Act directly becomes a bit trickier. There is also room here to be creative and to recognise that there is still human rights protection. Even in that private relationship, the care service is still providing a service that is regulated by the CQC, which is a public body that has Human Rights Act duties. The CQC should be stepping in and looking at what is going on there, as well as all the other public bodies that might sit on that care service—the local authority, the social worker.

There is a lack of recognition of the safeguarding obligation in the Human Rights Act. People talk a lot about safeguarding, but they do not talk about safeguarding rights. Yet if you are old enough to remember *No Secrets*, the original safeguarding guidance, the first paragraph talks about the positive safeguarding obligations being because of the Human Rights Act. There are mechanisms there that would enable a level of human rights protection still to attach in those examples, because that duty still exists for other public bodies and services that might sit around that private relationship.

There is also a practical element, which is the encouragement of proactive and positive practice. Very rarely would you have a care provider providing private care exclusively. You do not want them providing different levels of human rights-respecting care to different people in that service according to how that care is being paid for or arranged, so encouraging that level of consistent human rights protection is important. Historically we have looked at how we can plug that gap in the Section 6 definition.

I would also raise a very big warning flag right now, in that the Human Rights Act reform consultation by the Ministry of Justice outlines changing to public bodies and the definition. There is the potential for that to be seen as a positive and a way to increase protection, particularly in private care arrangements. Our view is that that is not what is on the table right now. Trying to restrict human rights protections more broadly as a way to fill this gap would set a dangerous precedent. So our recommendations would be about ensuring that all public bodies that sit around that private care relationship recognise their Human Rights Act duty to step in and safeguard.

**The Chair:** Thank you very much indeed. That concludes our questions to our first panel. We are very grateful to you for your evidence and, indeed, for your scrutiny and vigilance on this really important area and the work you do on it.

