HOUSES OF PARLIAMENT

Joint Committee on Human Rights

Oral evidence: Protection of human rights in care settings, HC 714

Wednesday 12 January 2022

Watch the meeting

Members present: Joanna Cherry MP (in the Chair); Lord Brabazon of Tara; Lord Dubs; Lord Henley; Baroness Ludford; Baroness Massey of Darwen; Angela Richardson MP; Dean Russell MP; David Simmonds MP; Lord Singh of Wimbledon.

Questions 8 - 17

Witnesses

II: Helen Wildbore, Director, Relatives and Residents Association; Caroline Abrahams, Charity Director, Age UK; Margaret Flynn, Safeguarding Expert.

Examination of Witnesses

Helen Wildbore, Caroline Abrahams and Margaret Flynn.

Chair: We move on to our second panel of witnesses, of whom we will ask some similar questions, following on from what the first panel told us. You have been with us and listening to the evidence of the first panel. One of you is a specialist in safeguarding and two are from organisations with expertise in supporting residents in care settings and their families. I welcome all three of you.

Helen Wildbore is a director at the Relatives and Residents Association. Caroline Abrahams is charity director at Age UK and a social scientist and a barrister. Margaret Flynn is a safeguarding expert with, like the other two witnesses, an impressive CV of experience in this area. Lord Dubs has the first question.

Q1 **Lord Dubs:** In our first panel, we heard from people with lived experience and, indeed, experiences that they found extremely painful. They were talking about issues that they faced in care settings relating to the protection of human rights. Are their experiences, in your view, an accurate reflection of the kinds of problems that patients, residents and family members face?

Margaret Flynn: They are indeed an accurate reflection, and I would extend the experience to people with learning disabilities as well as adults with mental health problems. The accounts are painful, yet they have a long history. We are talking, I know, about the impact of Covid on care homes, but we cannot set aside the fact that families have a pretty impressive track record of seeking to influence the care of their relatives in care settings and sometimes finding it extraordinarily difficult to do so. There is a history here. It did not commence with Covid, and a great deal remains to be unpacked if we are to see change.

Helen Wildbore: We know that a lot of good practice is happening. As has been said, care workers and managers are working really hard to make sure that people are treated with dignity and respect. The Relatives and Residents Association runs a national helpline specialising in supporting older people needing care in England, and we hear daily of the devastating impact of not respecting people’s rights, so I am speaking from that perspective today and sharing experiences of our helpline clients.

What has been said reflects what we are hearing. In terms of the prevalence of those experiences, right now older people in care are facing the most serious and most sustained attack on their human rights that we have ever seen. Fundamental rights like the right to life and well-being were neglected at the beginning of the pandemic, and people in care are still paying for the mistakes that the Government made as they then swung dramatically to the other extreme, placing the most stringent and far-reaching restrictions on those in care. In the name of keeping people safe from the virus, other rights are being violated and untold harm is being done to lives and to well-being. People in care are facing discrimination and are being left behind while the rest of the country gets back to normal. If this is what the Government meant by that protective ring, it is suffocating.

The pandemic has highlighted and exacerbated long-standing problems in the sector, not least staff shortages, as I am sure we will get on to, which are putting safety and dignity at risk. There are long-standing concerns about abuse, neglect, family contact, lack of liberty and autonomy, and what I would call everyday breaches of rights. They would not make the headlines, but there is a subtle erosion of a person’s dignity. Each time a person is dressed in someone else’s clothes or left without their hearing aid, that can have a huge impact on their well-being, identity and sense of belonging.

I would reiterate what was said about people in care being already placed in vulnerable situations due to the power imbalance that is written into the care system, and the lack of legal protection and security of tenure for care home residents. It means that too many are afraid to speak out or even to use their legal rights, which are already written down in law, because of fear of reprisals, including, as has been said, eviction. That has to change if we are to make rights a reality in care.

Caroline Abrahams: I broadly agree with my colleagues. Two big issues have come out. First, the quality of care in care homes is very patchy. There are 15,000 care homes in England. They are not all the same. Mostly, they are quite small operations, not run by big chains. They are small businesses. Some are quite good, a few are excellent, a lot are so-so, and some are not nearly good enough, largely because they do not have enough staff. Although all the talk in care is about the importance of personalisation and individualised care, particularly for very vulnerable older people with dementia, for example, the reality of trying to deliver that when you do not have enough staff to go around is really difficult. That is one set of issues.

Secondly, it was very interesting listening to the other witnesses that the word “control” came up quite often. The reality is that, for families who care passionately about the care of their older relatives, in this case, and have had control of it, the pandemic has flushed out the fact that, once somebody goes into a care home, they lose all control. It would be fair to say that families have no rights, and that has been very difficult. Older people have hardly any rights either, so it is a kind of rights-free zone. In terms of being able to apply any rights effectively, it is very shaky.

Put those two issues together and you end up with routine tragedies. This has been the most terrible time for older people in care homes, partly because so many people died particularly earlier on, which my colleagues have alluded to, but also because of the collateral damage from that, the consequences of the fear of repeating it, and the isolation of so many people, for whom seeing the people they love the most is the most important thing in their life. Take that away and very often there is not much left.

Q2 **Angela Richardson MP:** Thank you, panel. To what extent do you feel that care providers meet their obligations connected with the right to life, which is Article 2 of the European Convention on Human Rights? Is the right to life adequately protected in practice, considering concerns about "do not attempt cardiopulmonary resuscitation" notices—DNACPRs? Is adequate attention paid to the individual needs of patients and residents?

Margaret Flynn: I have a particular concern that inattention to people's routine healthcare has major implications for their right to life. There are too many occasions on which staff, regrettably, do not notice, or notice and do not take action, when it is very clear that someone's health is deteriorating. That is where the role of a family is so very important. As we have heard already from our colleagues, it is very clear that we know our relative's bodies, we know when they look unwell and we know how they signal, if they are not able to communicate, that they are not right. That essential information is not consistently valued, it appears to me, by care home staff.

There are many examples of this, not just for older people but for people with learning disabilities and with mental health problems, for example. It compromises people's right to life, most particularly when that persistent inattention leads to grave conditions. Even in the last couple of years, a number of adults with learning disabilities receiving full-time care have died as a result of complications associated with constipation, for goodness' sake. We have to look most particularly at how health is delivered, not just in nursing homes but in care homes, and how attentive staff are to addressing that.

Helen Wildbore: A lack of training on human rights, as well as on end-of-life care in general, is crucial to this question. It is putting people's rights at risk, with inappropriate, discriminatory use of "do not attempt CPR" notices, as we have heard. It is much wider than that. It is about the inappropriate withdrawal of care, and about ensuring that people are supported well in advance to start planning their own death and that their autonomy, wishes and choices about what that looks like are respected when it gets to that crucial time so that they are not making such fundamental decisions at a time of trauma and crisis. It is also about ensuring that discriminatory attitudes about older people do not lead to their health needs being overlooked, as has just been said.

All these things pre-date the pandemic but have been exposed and got a lot worse, as we have seen. We need to make sure that services are getting the support and training they need in order to respect this most fundamental of rights, but we have to remember that during the pandemic other services backed off from care homes, stayed away and left care staff to pick up the pieces. Care workers were expected to step in and fill those gaps, without necessarily having that training or the expertise and support to meet those demands.

Human rights, remember, were born out of crisis. In the aftermath of World War II, world leaders came together and recognised the need for really basic minimum standards—that is what we are talking about here—which we can expect even in the most challenging of times. Incorporating those rights into our law through the Human Rights Act has given care services not just values to turn to for guidance but a legal tool to help them make these really difficult decisions and to ensure that they are meeting those internationally set basic minimums.

Caroline Abrahams: There is a long-standing problem about healthcare in care homes that has been going on for years. It has got a bit better recently, and the pandemic did lead to some good practice, but the real problem is that most of the older people in care homes have complex, multiple health needs. They do not only have dementia in many cases. They might have heart disease or COPD as well and are typically in the last year or two of life, yet we are expecting care workers who are not clinically trained to be able to care for them and to spot emerging health problems. These are very often frail people, and being able to spot that pressure sore really quickly can make a huge difference, but often there has been only patchy availability of community health services and GPs.

There have been lots of rows about who pays for healthcare in care homes. In Germany, they have many more nurses who are absolutely part of the care home staff. As a society, we have not kept up with the changing and now greater needs of older people in care homes and have tried to care for them on the cheap with very poorly trained care staff. It is not the care homes' fault but the fault of the whole structure of care for this group of older people, and we need to have another look at it.

No one has said it yet, but the Government have been bringing forward some reforms to social care. As far as I can see, none of the reforms that they are talking about will make the slightest difference to any of the issues that we are talking about today. They are mostly concerned with how we pay for care. They do not address at all the quality of care. There is a bit on workforce but not very much, and it is all pretty much longer term. These are issues to which there is no immediate solution as far as this Government are concerned, unfortunately. We need to change that.

Q3 **Lord Henley:** We have been talking about Article 2. I wanted to move on to Article 3, but I think it has largely been dealt with. It is about whether people are subjected to inhuman or degrading treatment or punishment. To what extent have you noticed how care providers meet their obligations under that article, whether it is access to adequate food and fluids, medication or care?

Helen Wildbore: We hear, through our helpline, concerns about all the things you just mentioned—again, this predates the pandemic: the lack of food and fluids, abuse, neglect and poor care standards, such as people being left in their own bodily waste. The staff shortages I alluded to earlier are now reaching crisis levels. We are really concerned about care users receiving safe and dignified care. Those concerns are also coming through our helpline.

Relatives, friends and people who go in and support people using care services play a vital role in spotting potential human rights violations, particularly abuse and neglect. When they are locked out, either by bans, which we were hearing a lot about before the pandemic, or by the widescale restriction that we have now on meaningful contact, people in care lose this crucial support. They are their advocate or their confidante, the only person they might tell about concerns. That is why meaningful contact with the people who are most important to you is so vital, and that it is private so that you can have those private conversations.

Margaret Flynn: Mutually loving relationships, those that we have in families if we are lucky, clearly have an incredibly protective role. If that protective role is removed from the scenario, residents suffer. Regrettably, we also know that abuse continues. It has been with us for a very long time. There are homes where there appear to be no inhibitory brakes on this, which is why the absence of external personnel, be they relatives or other professionals, is particularly difficult, since humanity seems to be disowned in such settings.

Caroline Abrahams: So many older people in care homes and in nursing homes need help with eating and drinking. It is not a matter of just putting a plate in front of someone and letting them get on with it. They need somebody to sit with them and help them. It might take half an hour to help somebody to eat. If, as a care home, you are very understaffed, you probably just do not have the staff to do it. It is in those situations that we worry about people becoming undernourished and dehydrated. These are very real problems for people whose health is severely compromised if they are not adequately nourished. It can make a huge difference if people are helped to eat and drink, and it can be very pleasurable, but you cannot do it as a care provider if you do not have the staff. That is the problem.

Q4 **Angela Richardson MP:** Moving on through the articles, Article 5 of the ECHR ensures the right to liberty and security. What human rights concerns connected to this provision have you observed in care settings, particularly considering the use of restraints and of deprivation of liberty safeguards, which are established for the protection of people who lack capacity to consent to their treatment and care?

Caroline Abrahams: This is an area where, in theory, older people have some rights, which is brilliant. As I am sure you are well aware, the problem is that this system is in chaos. A new system was supposed to be coming in, but it will not be introduced for a while. Meanwhile, there is a huge waiting list to be processed and assessed to see whether it was right and proper that your ability to leave a care home was removed from you. In the vast majority of cases, I am sure that care home staff and others are acting absolutely in the best interests of people, but there is no legal protection for them if they have not been properly assessed by a trained practitioner, and there is a hugely long waiting list.

This is probably the area where older people have the most rights, but for many of them they are not worth very much because they cannot implement them. That is the sad truth of it. It is about underresourcing, once again.

Margaret Flynn: Seclusion is a topic that I find really exercises all of us. Is there any evidence that it works? It does very briefly, but only when people become exhausted and resist being in seclusion. There is no evidence that it has a promising therapeutic benefit, yet we know that the practice remains prevalent. We know that it is highly liable to being underreported and underdocumented, which troubles families no end.

There is also the very real possibility that cruelty can inform the use of restraint. We witnessed that, did we not, at Winterbourne View? Under the guise of restraint, staff were enabled to be extraordinarily cruel. Here is the irony: the failures of the CQC to withdraw registration can result because a service has ostensibly improved, yet this is a regulator that has neither overt nor strong features of challenge, which are so very necessary, particularly in relation to people’s right to liberty and security.

Helen Wildbore: I agree with what has been said. On the pre-pandemic point, I would add the everyday restraints. Lots of older people in care live behind locked doors, which can have an impact on their sense of it being like their home, their sense of belonging, and their general freedom and autonomy to make choices.

During the pandemic, we have seen severe restrictions placed on movements in and out of care homes for residents. What have been termed visits out of care homes do not capture it at all. What we are talking about is people being able to choose when and when not to leave their home, and being able to participate in the life of their community, which many of them will have been doing regularly before the pandemic, some with support and others not.

The government guidance has persisted with blanket rules on quarantine periods and encouraging providers to breach people’s right to liberty. Only recently did the guidance in England recognise that it would be unlawful to prevent someone leaving the place where they live if they have capacity to make that decision for themselves, yet the guidance is still putting in place blanket rules on isolation following what are called high-risk visits out, which include emergency stays in hospital.

This is about people’s liberty and autonomy, and their access to healthcare. We know that those isolation periods are preventing people getting the healthcare they need, because they do not want to face two weeks locked in their room when they get back to their care home. Access to healthcare, as you know, is fundamental to older and disabled people.

Q5 **Baroness Ludford:** We might have covered this question to some extent. We have covered various articles of the ECHR, but to what extent do you believe that care providers meet their obligations in connection with Article 8 on the right to private and family life, particularly with regard to visiting restrictions, evictions and closures of care settings?

Helen Wildbore: I will split my answer between pre pandemic and now. There were lots of concerns. This right is broad and covers many fundamental areas of importance for people. There were concerns about private contact to allow private discussions; about a lack of involvement in discussions and decisions that are made about your care and care plans; about being able to maintain relationships with people when there were bans of relatives and friends; about a lack of provision meaning that people are placed miles away from their family and being placed in care without consent; and, as you have said, about the catastrophic impact that evictions and home closures can have on people already in really vulnerable situations.

That was all pre pandemic. Bringing it up to now, with the visiting restrictions we have seen widespread infringement of this right. The term "visiting" does not do justice to this; it does not capture at all what we mean here. We are talking about meaningful contact with people who are most important to you, and maintaining relationships and lifelong bonds. Restrictions have had a hugely detrimental impact, not just on residents' mental well-being but physically. As we said to this committee previously, we know that people have stopped eating and drinking. They have lost weight, mobility and speech. They think they have been abandoned by their family and some of them have simply given up on life itself.

There is now lots of emphasis on protecting the right to life from the virus, but what about protecting to the right to life from isolation? This seems to be having a more detrimental impact than the virus itself. These restrictions are isolating for family members and friends on the outside too, locked out of the usual roles that they play as a loved one, as a carer and as an advocate. They are watching the decline from a distance, at windows. They are feeling guilt, they tell us, and pain, anxiety and frustration, but they feel powerless. People tell us that they are grieving for someone who is still alive.

Baroness Ludford: Thank you, Helen. That was very powerful.

Caroline Abrahams: I do not want to duplicate what my colleague said, but it is also important to remember that an older person in a care home has no rights of tenure. For us, this lies at the heart of some of the problems. If I rent a flat down the road, I have more rights to stay there than an older person has to stay in a care home if the care home wishes to evict them. As we have heard, if people are seen to rock the boat or their families are too difficult, it is usually very straightforward for a provider to ask somebody to leave, and it is difficult to resist that.

Given that this is somebody's home and is where they are living, it seems to us that, as long as older people living in care homes do not have rights of tenancy, you are asking for trouble on everything else, because that is fundamental to the balance of power between everybody in that situation. That is one of the things that we would like to see changed. It is a long-standing anomaly.

Margaret Flynn: Just to underline that, simply because somebody is admitted to a care home, that does not herald the end of the caregiving by a family. Families very much want others, most particularly the day-to-day support staff, to understand the worth of their relatives and, most particularly, to ensure that they are not harmed, yet there are no guarantees of either of those.

Q6 **Chair:** I want to come back to the crucial question, which we focused on with our earlier witnesses, of whether the Government have struck the right balance in the visiting guidance between the protection of the lives and health of residents, and respect for their family, private life and well-being. Have the Government got the balance right, or do you think, like our earlier witnesses, that we need legislation to get the balance right?

Caroline Abrahams: Throughout the pandemic, I have been on a cross-sector group trying to support and challenge the Government about visiting guidance. It has been a really interesting and very sad and difficult experience, for all the reasons we have heard today.

To start with, nobody much knew about the virus. Lots and lots of people died when their lives could probably have been saved. Since then, there has often been a sense of the door being shut after the horse has bolted and a real sense of risk aversion on the part of government and particularly, I suspect, of Ministers, who are desperate not to see that happen again. I can completely understand why.

At the beginning, I feel particularly that officials did not understand why it was so important for people living in care homes to keep in contact with their loved ones. We have heard about it all today, but that was much less visible to them. It is also important to remember that officials had been getting advice from all kinds of directions, including from Public Health England, which has generally been very risk averse. It is hugely expert on the virus but knows much less about the other issues that we have been talking about today, such as the importance of contact.

All those things have been playing out. In terms of where we are now, we know that omicron is killing some people in care homes, which is very sad, but, thank God, it is killing far fewer than earlier in the pandemic. It is still a risk to them, but on the other hand we have PPE, much better infection control, vaccination and testing. Sometimes the time lag between what we are doing for the rest of the country and what we are doing for care homes has been too long. I hope that the Government will look again at whether they can free up a bit more than they are at the moment. It has been very difficult throughout.

The other problem has been that the Government have confined their role to writing guidance, which has constantly changed over the course of the pandemic. It has often come out on a Friday evening. I am sure that is not the fault of the officials but because of clearance across government, but the end result is that, often, poor old care providers are being given a weekend to get to grips with quite lengthy, verbose documents. We could and should have been smarter at helping care providers to understand, very simply and concisely, what they had to do and what changes they needed to make.

There is another thing that we have asked for throughout the pandemic that has not happened. It is no good just giving care providers a document. We could be producing toolkits and all kinds of practical measures to support them in implementing it, but that has not happened either. I feel that it is a mixture of both the guidance and the implementation not being good enough.

Margaret Flynn: I would necessarily endorse that and would take the view that, for any guidance to be credible, it has to work for the individuals concerned. Does it make sense to older people, to their relatives and to the care homes themselves? We have heard this afternoon that clearly it does not, so we have to extend the membership of any such group that seeks to advance a particular way of working and to continue to engage them when change becomes necessary.

Scrutiny is a necessary safeguard. We have heard a bit about that today. Families have to visit. Ruthie and Sharon have made that case very powerfully. Families want services to be working and functioning, and we want our relatives to be safe. They are eyes and ears, indeed, and they have been underrepresented when they could have been in the foreground. That is where the guidance has let older people and other groups down most particularly.

Helen Wildbore: I will not repeat what I said earlier about the context of the mistakes and failures made at the beginning of the pandemic, and the terrible loss of life and dignity that we saw. We are now in the situation where the most severe restrictions in the country are being placed on care home residents. Even today, almost two years in, government guidance still contains blanket restrictions. It fails to balance the risk of the virus with the risk of isolation. We know that isolation is having a hugely detrimental impact, not just on well-being but on people’s lives and dignity, liberty and autonomy, as we have said.

Care providers tell us that they want to do more to facilitate safe and meaningful contact. They feel that they can do that in a safe way, but they feel shackled by the Government’s guidance. I would describe it as trying to wrap people up in cotton wool, which is simply not possible, not desirable and not lawful. Care homes are in communities. Care staff live in those communities and are free to mix, like the rest of us. Care settings are people’s homes, and care users have the same legal rights as everybody else.

Government guidance, from our perspective, needs an urgent and complete overhaul. It needs to start by recognising that care settings are people’s homes and that people living in them have rights, and then to use the framework that is already there, the Human Rights Act, to ensure that the restrictions are necessary but, crucially, proportionate to the risk. That change in approach and language would show the leadership that is needed to end the closed cultures that we have seen develop, and to give guidance and leadership to providers on complying with their legal duties.

This needs to change urgently. We are in an upside down world that is hugely damaging, where non-statutory guidance is being read as law and legal duties are being ignored. The CQC must take a proactive role here in monitoring compliance with that guidance but also with the law. We have been calling for it to do that for almost a year now.

We must never again see people separated from the essential support of relatives and friends. That face-to-face, meaningful contact with family carers should be seen as a prerequisite to basic good care. That needs to be recognised in law, with a duty on regulators to monitor and enforce that.

Q7 **David Simmonds:** This has been touched on to a degree in a number of the answers that have been given, but I wonder if you have a view on the reasonableness of a number of the things that have been imposed, which is a key consideration when it comes to their lawfulness, in the context of the guidance that has been provided on everything from self-isolation onwards.

Helen Wildbore: I feel I jumped the gun a little with my earlier answer, so I may have already covered it. People in care have faced much more stringent restrictions for far longer than the rest of the population. What we are saying here is that, for people who are living away from their families, their contact with those people is all the more important, more than for everybody else, because of the very fact that they are living away from them. We need to be doing more to make sure that those relationships are maintained and that families can play the vital role of family carer, family advocate, et cetera, as we have said.

The balance is all wrong. We have ignored the legal duties and the legal framework that are already there to provide us with the tools to do this. We urgently need to get back to those.

Caroline Abrahams: Through nobody's fault, a care home turned out to be one of the worst places you could be in during this pandemic. We did not know that before, but the combination of having lots of people living together in a congregate setting, who were also distinctly unwell and vulnerable to a horrible virus such as Covid, made for a very difficult situation.

One really difficult area is that the evidence, although we have not seen a lot of this published, shows that the real risk of transmission is from staff. Typically, staff in care homes do not live on the care home site but in the community. They have kids who go to school. It is not their fault that they would inevitably pick up the virus. Particularly earlier on, when we did not have the testing and the PPE, they were going to bring it into the care home. In a way, that is in with the bricks of the model of care homes and a particular issue during the pandemic. To a degree, it could not be controlled by any of the methods that were at the disposal of clinicians and public health.

What could be controlled was visitors coming in and out. There was an undue focus on that, but I suspect that the risk of transmission was far lower, because every person who cared about their relative in a care home would have done everything they could to reduce the risk. The last thing they would ever want would be to bring in a deadly virus to hurt them or, indeed, anybody else there.

I feel that because visiting could be controlled and so much else could not earlier in the pandemic, that was part of the general sense of panic, understandably. I have not looked at the latest death figures in care homes. The last time I looked, months ago, it was 40,000. Lots and lots of older people died in care homes, so a lot of people in positions of authority trying to make the right decisions here were frightened about seeing anything worse than that.

I do not blame them on one level, but a tragic consequence has been too much restriction on visiting at times. They have been too slow to act, particularly during the good times during this pandemic, in the summer months, when I always thought, "If only we could open up a bit now, because we might have to close down a bit later on, once the weather gets worse, and we know that the virus thrives in those conditions". We were sometimes too slow, in warmer weather, to open up and to give people more opportunity to see each other.

Hindsight is a marvellous thing, but we could have managed this better, and I am sure all this will be a big topic of discussion when we have the inquiry.

Margaret Flynn: Yes, indeed, and I would endorse everything my colleagues have said. The failure to give expression to the primary principle of people's welfare and well-being—those receiving care, including their healthcare needs and the need to be protected from home—was somehow set aside, which had grave consequences, most particularly for people with dementia who deteriorated. Families have been extraordinarily distressed to witness that from a distance and to know that their presence would have made such a positive difference to their lives.

Q8 **Baroness Massey of Darwen:** I want to focus a bit on discrimination and build on what I have picked up from some of the panel already. Article 14 of the ECHR clearly ensures the enjoyment of human rights without discrimination. Discrimination comes in all shapes and sizes. Helen said that staff in care homes should be educated about human rights and what they mean. Caroline talked about the implementation of good practice, not just by giving information to staff but by engaging them in what was important in dealing with people in the care home.

How much discrimination is there, and to whom? It seems to me that we have talked mainly about discrimination against older people or people with dementia, but also about discrimination against families and their efforts to help their relatives who are in distress. Are providers just unaware of human rights, or are they not aware of discrimination as a concept? What is going on here?

Caroline Abrahams: We have to remember that the rate of churn in care homes is about one in three. Every year, one in three people working in care homes move, so there is no continuity. That is also true among registered managers. In the end, the registered manager who runs the care home is probably the key person who determines the culture in the care home, and there is a great shortage of them too. Even if you train your staff, you might well find that they have moved off by the end of the year, so you have to have a very active programme of training.

It is fair to say that some care homes do embed human rights principles and train their staff, and they do care about these things, but I am afraid that that is not true of everybody. There is no effective implementation or enforcement of that. We have already heard that the CQC is absolutely not there to help people with individual complaints. Were they not cut in half a few years ago? They do not have the staff to do more than fairly light-touch inspections anyway.

David Simmonds, with his local government background, which I know about, will be particularly interested in the fact that there is no effective improvement mechanism in social care. There is something called the Social Care Institute for Excellence, which is a lovely but, as I think it would say itself, quite small organisation. There is no supportive, effective peer support asking, “How do we make everything better? Let’s all challenge and support each other”.

Let us be honest: the care sector is essentially a Wild West. It is highly fragmented. It is lots of small businesses. There is no registration of staff. Hardly any of it is state-run. It is almost all private providers and some not-for-profits. It is a Wild West and there are no rights, so are we surprised that we are where we are? There is a complete lack of framework within which to protect people at one of the most vulnerable times of their lives.

Margaret Flynn: I agree, Caroline. The regulation certainly has decreasing legitimacy, and we have to be very up front about that. I am interested that the Care Quality Commission is engaging in improvement activities and enforcement and prosecution activities in parallel. Those functions have to be functionally quite separate. You cannot do one and the other. We would not expect, for example, the Health and Safety Executive to be tasked with nurturing companies when it is prosecuting them. Care homes live with the consequences of that.

Helen Wildbore: I agree. There is a huge question to do with the discrimination that is faced in care settings. All three of us could probably talk all afternoon about the many identities that people have and how they are protected in law through things such as the Equality Act—not just being an older person or a disabled person but in terms of race, ethnicity, sexuality, sexual orientation and the rest of it.

To focus on one of those, every day on our helpline we hear about the lack of support for some of the most basic accessibility needs—I mentioned hearing aids earlier, but there is also glasses, dentures and mobility aids—to ensure that they are there, they are working, they are clean and they are found when they go missing. These things can seem really minor, but when they are not there they have a hugely disproportionate impact on people's quality of life and their everyday life.

In terms of the training that you asked about, I would say that there is a widespread lack of knowledge of human rights among care staff that needs to be addressed urgently. There should be managed training on human rights and how it interacts with other laws, such as the Equality Act, which has been mentioned, and the Mental Capacity Act, not just to understand and comply with their legal duties but so that care staff can understand how to use those laws in practice to improve services and to improve people's quality of life. It is not just for care workers but for commissioners, social workers, health practitioners and inspectors.

Just picking up on a couple of the points that Caroline made, these are long-standing problems. The long-standing problem of staff retention also needs to be addressed urgently if we are to make any headway with any of this. We should be doing what we can to make sure that that knowledge, expertise and skills stay within the sector. Care workers need to be properly rewarded. This is a crucial public service. There needs to be a nationally recognised career structure, as there is in the NHS, with mandatory qualifications, so that care workers become as highly valued as their colleagues in the NHS for carrying out the vital work that they do.

Margaret Flynn: There are labels in addition to diagnoses that render some people yet more disadvantaged. The label that I would particularly go for is "challenging behaviour". In my experience, people whose behaviour is perceived as challenging are subject to many more restrictions than others. In terms of how we deal with that, there is a real problem with the very fraught boundaries between personal responsibility, the regulation of the CQC, professional regulation, and not just human rights but the contribution of the police and safeguarding, and complaints. It is very messy. There is no simple map that we can give to patients and residents and their relatives, and say, "This is what you do when something happens", because it is very messy.

Chair: Margaret, Helen and Caroline have answered this question already, but I just want to be clear that we have your view on it. It is about training, but particularly the training of care staff in relation to human rights considerations. Are care staff adequately trained in relation to human rights considerations?

Margaret Flynn: No, they are not. If anything, there is usually a paragraph on human rights that sits in a policy called safeguarding, and that is it. The training has devolved and has now become e-learning. People do it at home, when they can, and we are not really that interested in whether they have followed it. I am afraid that things have diminished a great deal in training for staff. Turnover is a huge problem when it comes to keeping staff up to date.

Q9 **Lord Brabazon of Tara:** Returning to the issue of complaints, which I asked the first panel about, are regulators such as the CQC effective in their role as watchdogs for care residents, patients and family members? Do you believe that individuals have at their disposal mechanisms that ensure that complaints are investigated and dealt with anonymously and effectively?

Margaret Flynn: The procedural rigidity of the CQC is at issue here. It does not investigate complaints and, as we have already heard, people are bounced from one organisation to another. I know that some complaints have gone unresolved for many, many years, and families are left feeling extraordinarily frustrated and with a sense of strong grievance. The CQC has not assisted families on this front.

Homes themselves might undertake a complaint investigation. That does not give the families much confidence that they will do it fairly or that they are sufficiently impartial, and it can take many months for matters to be resolved.

There is a great deal that we should expect the regulator to do to direct people and to offer people assistance but which it is not currently doing. If anything, what I have learned from this is that families are such stubborn advocates. They very much want things to be right for their relatives, yet they do not have people alongside them to assist in challenging extraordinarily poor and, very occasionally, abusive practice. It is not enough just to go to the CQC or to go to the home. Changes are not realised in that way, regrettably.

Helen Wildbore: Where to start on this? I will try not to take up too much more of the committee’s time. Older people have been failed by the systems that are designed to protect their rights during this pandemic. The CQC is a major part of that. Its lack of action, as it witnessed this human rights crisis unfolding in care, has left people at risk. It stopped its routine inspections. It failed to act as the voice of the sector to challenge mistakes that were repeated. It failed to step in to end the systemic human rights violations that we have been talking about.

We wrote to the CQC twice during the pandemic to express our disappointment in its role. We encouraged it to take action, including a proactive role in monitoring compliance with the visiting guidance, but to no avail. As has been said, it does not take complaints. It asks people to feed back on care. We have raised concerns with it about how that information is then used in such a way that inadequate action is taken, and there is failure to ensure that care users’ anonymity is protected, which puts them at risk of reprisals, and a lack of follow-up with families, where you just hear nothing back and you do not know the outcome. The action taken has become a bit of a postcode lottery. When they act adequately, things get changed very quickly. We want to see more of that, but it is a complete mishmash at the moment, depending on which inspector you get.

The sector really needs better and more robust oversight. We need more frequent inspections, not fewer. We need the CQC to build back trust among care users and their families. We also need a central responsive complaints procedure with the powers to bring about meaningful change. When care users and their families are facing poor care, which is a stressful and traumatic time, it should be simple and easy to get the support that they need from a body they trust to act quickly and effectively.

Caroline Abrahams: At a risk of mixing two things up here, which are regulation and inspection on the one hand and complaints on the other, I do not see the CQC as being in the game of complaints. It is about inspection and regulation.

On complaints, let us remember too all those older people who do not have anyone to advocate for them. It is okay if you have Ruthie, Helen or other strong-minded family members who can stand up for you as an older person, where you no longer have the capacity to do it for yourself, but there are lots and lots of older people in care homes who do not have anybody. What there is not is proper advocacy that is a part of the mix. They are the ones who, arguably, one should worry about the most, because there is nobody there to stand up for them.

Trying to take a complaint of any kind against an individual care home or a local authority is a heavy-duty thing to do and takes a long time, as well as a lot of effort and energy. Ultimately, you can go to the ombudsman, but that takes ages. Let us remember that the average stay in a care home is 18 months to two years. People need quick answers to problems. There is no point being embroiled in some lengthy process that does not conclude until after your loved one has died. It is another area that needs a proper look.

Q10 **Lord Singh of Wimbledon:** I would like to thank the panel for their very patient, helpful and moving answers. My question is also related to the complaints procedure mentioned in the previous question. Are there effective human rights protections and mechanisms for complaints from people in private care and other alternative settings? Should all care providers be subject to obligations under the Human Rights Act?

Caroline Abrahams: No and yes. One thing we have not mentioned is that if you are an older person in a care home and paying for your own care, you are not covered by the Human Rights Act at all. Only people whose care is paid for by the state are covered by the Human Rights Act. There is a big anomaly. You could have two older people in adjacent rooms in a care home with exactly the same issues, and only one of them could use the Human Rights Act, even if they were minded to do so. Again, Age UK has called for years and years for change in that. It is a nonsense. That would be a very simple and obvious thing to do to make a bit of a difference.

Helen Wildbore: On the first question about complaints, no, there is no adequate complaints procedure. Families are often left bereft when they feel that they have to raise complaints. There is a lack of support. Even in an organisation that you can turn to, where do you go to make your complaint if you have made it with the care home and the local authority and you are getting nowhere? That needs to change urgently.

The duty under the Human Rights Act should apply to all providers of care, regardless of how that care is arranged or funded. At the moment, if you are privately funding and arranging your own care, when your human rights are being breached you can try to go directly to that care provider and talk to them about human rights and the law, but if you want to use and rely on your protections under the Human Rights Act you have to get a core public authority involved—the local authority, an NHS trust, a commissioner or the CQC.

Someone who always has a duty under the Human Rights Act to respect and protect rights needs to be in play for you to enable you to rely on your human rights. That is just too complicated for families in stressful, traumatic situations where your rights are being infringed and you need an urgent solution. The duties should just lie on everyone who is registered with the CQC.

Lord Singh of Wimbledon: It would be a wonderful world if all provisions of human rights were respected. That is my own comment, but thank you again.

Chair: Thank you to all our witnesses this afternoon. You have given us a lot to think about and very thorough answers to our questions from a number of perspectives. It has been immensely useful to all of us in our deliberations, so thank you very much indeed.