HOUSE OF LORDS

Revised transcript of evidence taken before

The Select Committee on the Equality Act 2010 and Disability

Inquiry on

EQUALITY ACT 2010 AND DISABILITY

Evidence Session No. 19 *Heard in Public* *Questions 166 - 173*

TUESDAY 8 DECEMBER 2015

4 pm

Witnesses: Ms Emily Holzhausen OBE, Michèle & Andrew Brenton, Jeanine & David Blamires

Members present

Baroness Deech (Chairman)
Baroness Browning
Baroness Campbell of Surbiton
Lord Faulkner of Worcester
Lord Foster of Bishop Auckland
Lord Harrison
Baroness Jenkin of Kennington
Lord McColl of Dulwich
Lord Northbrook
Baroness Pitkeathley
Baroness Thomas of Winchester

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Examination of Witnesses

Ms Emily Holzhausen OBE, Director of Policy and Public Affairs, Carers UK, **Mrs Michèle Brenton**, **Mr Andrew Brenton**, **Mrs Jeanine Blamires**, and **Mr David Blamires**

Q166 The Chairman: Good afternoon, everybody. Thank you very much for making the trip to come and see us. We particularly wanted to see the five of you because the written evidence you sent to us was so persuasive and interesting, we thought we would like to hear some more from you. Particular thanks to you for coming.

I should say to you that this session is open to the public. A webcast of the session goes out live, and is subsequently accessible via the parliamentary website. A verbatim transcript will be taken of the evidence, and will be put on the parliamentary website. A few days after this session you will be sent a copy of the transcript to check for accuracy. It would be helpful if you could advise us of any corrections, as quickly as possible. If, after this session, you want to tell us some more, clarify or amplify something—because, as you know, we have not got that much time, you have to be fairly concise and it may be that as soon as you leave you think, "Oh, I wish I'd said this"—do please write to us and we will take it on board. There may be some votes this afternoon, which will be evident to us from various scenes on these screens. If you find people stand up and walk out, that is simply because they have to go and vote. We will adjourn for a few minutes to allow people to go downstairs to vote and come up again. That is all it is.

I would like you to feel relaxed and comfortable. If you want to pause for a few minutes, pop out to take a deep breath, whatever, please do feel free to do so. Do not put yourself under any discomfort. Whatever it takes to make you feel able to give us the full benefit of your experience is fine by us.

We have got about five questions for you. Perhaps you would like, briefly, to tell us who you are, starting with Ms Holzhausen.

Emily Holzhausen: Thank you for inviting us to give oral evidence, we very much welcome the opportunity. Carers UK was set up nearly 50 years ago by a woman who had to give up work in order to care. We were founded on a very strong rights base, and that still continues very much today. We are a membership organisation of carers run by directly elected carers. Our evidence is not just from policymakers and practitioners; our evidence comes largely from people themselves. To us, the Equality Act was an incredibly important step in the

journey of rights and visibility in society. I think your inquiry is quite right to look at whether that has been implemented for disabled people and their families.

The Chairman: Thank you. Michèle and Andrew Brenton.

Michèle Brenton: Thank you for inviting us here today. I am Michèle Brenton. I am Andrew's wife. I am somebody who has spent decades being a carer and, for the most part, not realising I was one at the time. That is something I realised quite late on in the situation, and, during that time, my own life and ambitions and interests dwindled until they have practically disappeared. Here I am, wife, mother, and not a lot else at the moment.

The Chairman: Anything to add, Mr Brenton?

Andrew Brenton: I am a multiply disabled person who has been on the end of direct discrimination from a university and had the struggle of trying to get things put right, trying to get inequality and discrimination sorted out, and found it is extremely difficult and extremely tiring.

The Chairman: I know that some of you are involved in cases of one sort or another, therefore you will not want to go into the details of them while they are still under consideration. We can talk in generalities, and if there is a question that you think is too probing into your case, you do not have to answer it. Mr and Mrs Blamires.

Jeanine Blamires: I am Jeanine Blamires. This is my husband, David Blamires. I am a disabled person who also happens to be a parent carer. Apparently, I can be either a disabled person or a parent carer; it appears that I cannot be both. I have been sick for 16 years with the condition I have, chronic fatigue syndrome, plus a few other bits and pieces, which you will notice from the involuntary movements that I have. We have two daughters, one who has complex difficulties, but is high functioning.

Our biggest issue at the moment is enabling our daughter's aspirations to be achievable, because the organisations out there, that are supposed to enable her to achieve as best she can, do not have the same aspirations. We would like to see that change.

David Blamires: I am a carer. Much as Michèle said, I fell into this role. Without offence, it is not one I would have chosen. Please excuse the glasses. I suffer from chronic pain and these reduce it a little bit so I can actually function. Unfortunately, I am at the stage where painkillers only cause more pain, so they are barely worth the effort these days. If I sound a little sharp or aggressive, that is the pain speaking; that is not what I mean to sound like. Please bear that in mind and listen to the content, not the tone.

Q167 The Chairman: Thank you. We have some questions for you. If anyone has relevant interests to declare, they will mention them before they put the question. I said some people might have to go out to vote; some people have to leave early or whatever, so do not take any notice if somebody has to go out briefly. You do not all have to answer every question, but if you have something to add, please do.

The first question is from me and it is to the Blamires and the Brentons. Both of your families have experience of challenging disability discrimination, and have faced barriers when doing so. What changes would you like to see to the court process to make it easier for disabled people to access their rights? Would you have preferred to have been able to go to a disability ombudsman or a body that could offer mediation? Who would like to answer that one?

Jeanine Blamires: Could I answer that one? It is quite current. Can I split it with my husband; he is going to tackle the ombudsman issue. My experience is quite raw and still current. The biggest barrier to enabling a disabled person to achieve any sort of access to the court process is information. Information is so poorly written and so poorly presented on the

Government websites, which are supposed to be there to enable us access; in effect, they are a barrier to accessing the court process, and that must change. To be frank, if I had the energy, I could sue the justice.gov website for being inaccessible for a disabled person. I should not be here saying that.

David Blamires: You should not have to say that.

Jeanine Blamires: We live in an area where accessible advocacy is hard to obtain. We have attempted to get help from Mencap, Disability Rights, the Equality Advisory and Support Service, Liberty and many others. Complex cases are not being put through because the money is not there to support organisations to take them on. Complex cases are being ignored by the Legal Aid Agency; they are too expensive. It takes too much time to go through them, pull out the strands and see where the problems are. It is impossible.

I need to say, two years ago when this started my speech was extremely poor. I have had my head rewired since—I am not sure for how long—but while I can speak I must say how horrible it is to try and make yourself understood on the phone to people who are not prepared to put the reasonable adjustments in place to enable me to communicate, so they misunderstand and misinterpret. You get told, "No". Then you say, "You didn't understand". "We did". "You didn't understand, please let me explain". Again, they are not hearing you. There is this criterion within the civil legal aid law that if they cannot follow the instructions of the applicant it must go to face-to-face. That is not happening. That did not happen in my case. I think the legal people have pointed out problems there previously. There must be some form of advocacy, whether it is through legal aid or on the doorstep, like it used to be through the citizens advice bureaux, somewhere you can go and say, "Help", and they can say to the organisation, "Come on, all this person needs is to be able to communicate to you the problems she or he is having. How can you facilitate to enable this person to be heard?" That is all it takes, and then for them to do it. That is impossible at the moment.

I will also add—I know I am going on—if at all possible if I could get advocacy in another district, it would be helpful. There is advocacy available in law centres elsewhere but they are postcode restrictive; they are funded by different councils, so I cannot go there. If I have a complaint against my own council, it is a conflict of interest to go to an advocacy service funded by them locally. It causes problems, and has in the past. There must be some form of mechanism, if there is a perceived or obvious conflict of interest, for that person, family, or child, to go over the border and access advocacy from another service. That would solve quite a lot of issues.

I have got quite a lot more here, but I need to allow Michèle to have a say.

The Chairman: Someone was going to tell us about the ombudsman issue.

David Blamires: I can speak on that one. As at this moment, we are suing one ombudsman for discrimination, we have cases stalled with the Parliamentary and Health Service Ombudsman and the Energy Ombudsman because they will not make reasonable adjustments. Ombudsmen are reactive, not proactive. Both Jeanine and I come from an educational background and, much as I am going to get a lot of angry teachers here, the Ofsted-type model of proactive assessment is very effective. Teachers hate it, but it does work.

On the point of mediation, mediation as part of the process is fine, but it does imply there is fault on both sides almost by its definition. As a general rule, discrimination is quite black and white; it either is or is not. From what we have gathered over the last two years, it is one of those areas of law where it is less about how it is interpreted and literally more about

how it is laid out on paper. Mediation as part of the process, yes, but it must be face-to-face and wholly independent of any influence.

With respect to the comments on the Parliamentary and Health Service Ombudsman, the ombudsmen we are suing have committee members on the Parliamentary and Health Service Ombudsman and they are slowly merging together. It does beg the question: is there a conflict of interest? It leads me back to my point on an Ofsted-type assessment.

The other thing we thought of was the Information Commissioner's Office. A lot of discrimination is information based. Whilst lifts and ramps are big-ticket items, they are simple things to fit. Attitude and persuading people to change what is, quite frankly, centuries of ingrained attitude is going to be the biggest trick. It has been done with most of the other discriminated groups slowly over the last 50 to 100 years; it needs to be pushed further with the disabled. We appear to be the last whipping boys left.

The Chairman: Good point. Anything to add, Mr and Mrs Brenton?

Michèle Brenton: With regards to the court forms, et cetera, it is not as big a job as it might seem to make these accessible. One of the problems is it sounds like it is a huge immovable task, but if the will is there an awful lot of these things can be fixed with five minutes' common sense and consideration. For example, on the court website, we had our remission fees claims rejected, at one point because we had used the form that was online and it was out of date. It is simple things like that—keeping websites up to date—which is something you would expect would be a baseline. It causes a huge problem. Information is not available to the court people themselves. The second time we had a court remission fee nearly bounce because the clerk we handed it to did not understand the banding fees. We nearly timed out because of that.

That brings me to the other point, which is timing out. The timing out period is much too short. It is six months, as far as I understand, and that is nowhere near suitable. Disabled people are already dealing with challenges in their lives day-to-day anyway, and they then undergo disability discrimination which has various levels of impact upon them and they have to get their heads together to decide whether or not they are going to go to court. This takes time and consideration. They may be emotionally and physically impacted by the discrimination. They may not be able to think clearly. By the time they get themselves organised, looking for representation, advice, et cetera, that six months is a very narrow squeak. It can take quite a long time for the effects of the discrimination to manifest themselves, particularly physical manifestations of stress, et cetera, with ongoing long-term harassment. I am talking from a litigant in person's point of view now. You do not understand, you put your case together and, as far as you are aware, once you have done that it is carved in stone, and changing things as you go along is very difficult. It is hard enough getting there in the first place without making alterations as you go along. As the time goes on, if something appears, like a physical problem, you tend not to want to add it because it is going to complicate the situation and make what would have otherwise been a straightforward case into a complicated case. It snowballs and gets very confusing and complicated. If you had a longer run at it, you could probably get your case clearer and have all your ducks in a row properly. That would make life easier for the courts as well as the litigants, because there would be fewer complications with things arising as you go along, because you would have a longer time to do research and see where you were before you went in.

The problem with ombudsmen is when discrimination is impacting upon somebody's studies, as with my husband and now with my son, it is ongoing while something is running

alongside it. I presume it is similar with employment discrimination as well. You are afraid to rock the boat because it can damage something you still hope will turn out well and do not want to cause a problem with people thinking you are troublemaker. If ombudsmen were fast and had a kind of triage system, that would help. If you had a discrimination situation which was a one-off situation, that could go on the backburner because it is over and done with; it is all over bar the shouting and how it is going to be sorted out. If it is still impacting on somebody's life, snowballing and getting worse and worse, that is something that needs to be nipped in the bud. A triage system might say, "We will speak to you first and see if we can sort something out fast". That is what I would say about ombudsmen.

We would have liked to have gone to a disability discrimination ombudsman if they could have moved faster and sped things up and we could have solved the problem. The most important thing for us was to solve the problem, not to get compensation after the fact, because by that point the damage is done. At that point you are acting altruistically, trying to get things changed for other people, because the damage has been done for you and cannot be undone and no amount of money can fix it.

Jeanine Blamires: Can I comment on that?

The Chairman: Can we just hear from Mr Brenton first and then we will come back?

Jeanine Blamires: I am sorry.

Andrew Brenton: I would like to add to that. As far as I am aware, the only redress is through civil action, for which you will not get legal aid because of the complexity. The Civil Procedure Rules are really complicated. I count myself as a reasonably well educated person. The first thing that an institution will do is engage the most expensive lawyer they can to try and frighten you, which is what happened in my case. My court case is settled and over, so I can talk quite freely about it. They engaged a firm of London solicitors. One of the first things they said was, "You're not doing it according to Civil Procedure Rules. You've gone wrong this, that and the other way. By the way, our fees are likely to be somewhere in the region of £65,000. When you lose, you'll have to pay that". It is going to frighten off a lot of people, and I believe that is the objective.

The next thing that happens is they do something called a Part 36 offer, which is a payment into court that the trial judge is not privy to. If it goes to full trial and you are awarded less than the best Part 36 offer that is in force, you will probably have to pay the defendant's costs even if you win. In my case, they made a very low Part 36 offer, which they subsequently upped. It is playing fees roulette, almost gambling on what the judge is going to award. There is no clear scale of compensation. The compensation is usually based on the Employment Tribunal, on something called the Vento scale, and the lowest to the highest is an extremely wide band. You are trying to second-guess what somebody else is going to think of the injury to your feelings, which is not something you can be objective about. By its nature, an injury to your feelings is very subjective. That is the second part. The Part 36 is another way of pressuring you to settle for an unreasonable amount.

The Chairman: We have heard quite a lot about costs. We know that is a problem.

Andrew Brenton: In my view, in the case of discrimination under the Equality Act, it would be beneficial if the Civil Procedure Rule Part 36 was not allowed, so there could be no offer into court. This would immediately put the defendant at risk of costs, which would focus the mind.

The other thing that happened to me was their main line of defence was, "You are not disabled". Despite providing them with a lot of evidence, the university taking money to provide services for my disability—I had a disabled students' allowance, a disabled students'

needs statement, at the time I was in receipt of disability living allowance at medium rate care and full rate mobility—their first line of defence was, "You're not disabled. You've got to prove you're disabled". It adds a further layer of harm.

The Chairman: We have heard that problem very forcefully.

Andrew Brenton: It is very, very distressing.

The Chairman: A final quick word from Mrs Blamires.

Jeanine Blamires: The judicial process is not bound by the Equality Act. It needs to be. They try to compensate for it with their equality handbook. It is possible for solicitors, defendants, respondents, to continue discriminating while the court is in process and that affects the overall objective of being able to settle and save on costs. We cannot go much further than that. All parts of the court process must come under the Equality Act so that you know once you hit the court process you are safe from discrimination, and at the moment you are not.

Q168 Lord Faulkner of Worcester: Before I ask Mr Brenton a question, could I offer my congratulations to him on securing his postgraduate degree, despite these extraordinary difficulties he must have experienced in the process? That is an inspiration to everybody. We understand that you challenged the university on making reasonable adjustments for you because you wanted them to change their policies, not just for you but for other students. Has anything happened since you graduated? Are other students experiencing the same sorts of problems as you did?

Andrew Brenton: In my opinion, the university has paid lip-service to changing. They say they have changed and rewritten some of their equality policies. I have it from an extremely reliable source that students are still being discriminated against, both through learning difficulty and physical access. I have it on authority that one of the university's newest buildings is not wheelchair accessible in the way that it should be. My son is still being discriminated against with regards to his neurodivergence and learning difficulties. It is still going on.

This is possibly a problem with the attitude of senior management. They are fairly divorced from the learning experience, because they sit quite a way above the lecturing and contact levels. When I spoke to them wanting to drive change, to eradicate the problems, they saw that as me being somewhat of a nuisance, and it was discussed amongst themselves. I have been privy to all the emails through a subject access request under the Information Commissioner's Office's policy.

Lord Faulkner of Worcester: Freedom of Information Act.

Andrew Brenton: It was actually under the Data Protection Act. At one point, they decided that my complaints—and my complaints through the internal complaints procedure were upheld—were vexatious and I was a troublemaker. They tried to create this scenario where they could stop listening to me, because I was being a nuisance, when these were very, very real problems.

Lord Faulkner of Worcester: I should have declared an interest as vice-president of the charity Level Playing Field at the beginning. I am attempting to get legislation through Parliament regarding access for disabled people to sports grounds. Can I ask you another question, Mr Brenton? Did anybody explain to you that you could have applied for an injunction to make the university carry out the reasonable adjustments that would have helped you?

Andrew Brenton: No, because we did not have anybody that could advise us. When I went through the internal stage 1 and stage 2 complaints, the university clearly instructed me the next course of action that I could take against them was to take it to the Office of the

Independent Adjudicator, which is effectively the university's ombudsman. We knew at that point the university's ombudsman had made a statement that they will not judge on cases of discrimination—they see that for the courts—because of the complexity. If I had taken it to the Office of the Independent Adjudicator, the case would have timed out because they take 12 to 24 months to go through their process. The issue that Michèle brought up of the statute of limitation on bringing a claim is very real and valid, and, in my opinion, it needs to be somewhere nearer three, four or five years. It is quite hard to bring a case against a university where you are studying, because you fear they may take retaliatory action by penalising you academically. They did not.

Michèle Brenton: We did know that an injunction was available, but they kept saying they were going to get it fixed. It was always, "It'll be done in a minute. It'll be done in a few days. It'll be done in a month", and it just dragged on and on. By the time we were at the point when we would have thought about going to an injunction, that was the point when it did get fixed. By that time the discrimination had moved on and was not just the physical lack of access that had been the problem; it had now turned into something a lot wider and the discrimination was turning into the way Andy was being treated personally and being called into meetings, which arguably could count as harassment. It was turning into a very nasty, unpleasant, stressful situation.

Basically, Andy was getting up in the morning, feeling sick with nerves, going into university, doing what he could, keeping his head down, trying not to make a fuss, even though he would go into a lecture and the lecturer would not face him. He is deaf, and they would not face him so he could see their lips. Or they would give a film to watch and there would be no subtitles, so he would have to leave because there was no point in him sitting there. If he left, because there was no point in him sitting there watching a film he could not understand, he was treated as though he was being unreasonable and disruptive. This was the kind of thing that happened over and over. This was the baseline level of discrimination that was background constant noise all the time.

He was called into a meeting at one point, which he thought was a meeting with two people to discuss how to support him, and it turned out he was facing seven or eight people, was it?

Andrew Brenton: Seven senior managers.

Michèle Brenton: Seven senior managers, who basically grilled him. I have actually got the transcript of that. By this point, things were so bad Andy was carrying a recorder to protect himself, because we did not know what was going to happen next. He was coming home at night, debriefing with me—I was trying to take some of the flak off him—and then was going straight to bed. We had no life. He has chronic pain anyway, and it is made worse by stress. What was supposed to be three years of him being a student and us having a fairly pleasant time of it turned into hell on wheels, frankly, and our lives were awful.

Q169 Baroness Pitkeathley: I have to declare an interest as vice-president of Carers UK. My question is initially addressed to you, Emily. The concept of "discrimination by association" protects carers from being discriminated against because of the disability of the person they care for. Do unpaid family and other carers know they have such rights under the Equality Act? Does the Act provide enough protection for carers who are themselves disabled, as we have colleagues with us here today?

Emily Holzhausen: I do not think I could possibly be accompanied by two better examples than Michèle and David. The vast majority of people who do care, as many of you will know, do it as part of a close relationship, either as a family member or close friend. People do not call themselves carers, or use that label. Generally, people find it quite hard to find out

about their rights and entitlements. From the outset it is difficult. To understand the concept of discrimination by association is quite a leap for most people. When you read the legislation, and Section 13 itself, it is quite difficult to understand until you get into practical examples of how somebody talks to you in a very negative way because your son has a learning disability. Another example raised by one of our members was a health professional saying, "Well, it's not worth you having the operation because you're caring for your husband, so you won't have any benefit from it". It is those sorts of things, everyday discrimination, which disabled people recognise very well, and the impact that goes beyond just the disabled person. That is also the whole point of this: if the person in your family or your close friendship is disabled and they are discriminated against, it impacts upon you directly.

To come to the particular point of double discrimination, we find a lot on our advice line and some assessment processes through local authorities where people do not necessarily understand that you can have a disability and still be a carer. It is possible. Equally, in the benefits system it is possible to have a disability and be a carer and get PIP as it is now—personal independence payment—and carer's allowance. It is possible to do both, just as it is possible to have many other roles in life at the same time. There is still a big awareness job to be done to understand from the family's point of view, but also for everyday services and professionals.

Baroness Pitkeathley: Mr Blamires, would you like to comment?

David Blamires: I have got one line. This is literally the first time I have heard of this, and I have been caring for either my wife or daughter for 21 years. I accept the Act only came in five years ago, but this is a revelation. I am not amazingly well educated, but I have worked in education and am not uneducated. It does not appear to be readily available information and needs to be pushed a bit more. That is pretty much all there is to say.

Jeanine made a point in our notes. As far as we can determine, I am effectively a slave to the Government. The premium comes to £30 a week. That is broadly slavery in any other terms.

Baroness Pitkeathley: Thank you. Mrs Blamires, would you like to comment?

Jeanine Blamires: They removed evidence that I was a disabled carer from my daughter's social care records. That caused me harm.

Baroness Pitkeathley: They removed it?

Jeanine Blamires: They removed it. They removed my husband's difficulties too. When you are a parent carer and you have a disability, if you are not assessed for the help you need so you can be a better parent, you cannot be a better parent. In effect, you are set up to fail.

David Blamires: If you ask for a reassessment, in our case they threatened, "Well, you'll get less care because we're having budgetary restrictions". You are left with your backs to the wall and the ground in front of you falling away. It is quite uncomfortable.

Baroness Pitkeathley: I am sure it is.

Jeanine Blamires: Can we put our area in context? In North Yorkshire there is a problem. North Yorkshire is the area where they went to court to get permission to, in effect, imprison a young man in his own home. This is North Yorkshire County Council v MAG, which you will find on Steve Broach's blog, "Rights in Reality". I will send you the link. Every day we deal with that mentality where all efforts are put in place to make it as difficult as possible for people in North Yorkshire, who have needs, to get those needs met. Our needs are seen as a cost. They do not look at us and see the benefit we can bring to the community.

Baroness Pitkeathley: Or indeed the value of your contribution. Thank you very much.

Q170 Baroness Thomas of Winchester: My question follows from the last. First, I must declare my interests. I receive DLA. I am a trustee and vice-president of Muscular Dystrophy UK, a member of Lord's Cricket Ground Disability Access Committee, and a patron of Thrive.
Is there a need for carers to have the same right to reasonable adjustment as disabled people? How significant a problem is it that the Act does not currently require this? Would such a provision be the most effective solution? Perhaps I should ask Emily first of all.
Emily Holzhausen: Thank you for asking that question. In reading the Equality Act—and I still maintain, despite some of the issues of implementation, the DDA is an incredible step forward, as was and is the Equality Act—I thought part of that would naturally lead to reasonable adjustments. I had a good discussion with the lawyers about that. Because it is not inherent in the law there is no direct right to have reasonable adjustments, only to not be discriminated against by being associated with disabled people. Even the concept of indirect discrimination is not there for carers. I would say the best implementation of law is something that is easy and readable. A step towards reasonable adjustments for carers would be a positive step forward.
I also wanted to put this in context, if I may. With an ageing society, and people living longer with disabilities, it will become much more commonplace for people to be working with disabilities, or caring for somebody and looking after somebody at the same time, so we should put these measures in place to be able to keep people working in jobs that they wish to do for longer.
Q171 Baroness Thomas of Winchester: That is a very good point. Could I put my next question to Mrs Blamires? In your evidence, you talk about the needs of your household rather than each individual within it.
Jeanine Blamires: Yes.
Baroness Thomas of Winchester: For example, when a missed hospital appointment may be due to your own disability or that of your daughter. Should the hospital look at reasonable adjustments for the carer as well as the patient?
Jeanine Blamires: Yes, absolutely. The example I have has come up today but it is not a hospital.
David Blamires: In the last 24 hours.
Jeanine Blamires: It is education. My husband says it is applicable. An appointment has been arranged for my daughter's EHC plan without discussing with us if it is a good time, and it is not. My autistic daughter is very unhappy and making her unhappiness known, as autistic young people do. We have to deal with that. There are things I have to do for her, whether it is social care or health, and, because I am like this, my family needs to do for me. We are constantly juggling balls in the air, whether it is court cases, social care or health care. I am repeating myself. They are all on the calendar. When people ring up or send an appointment through, literally we have to ring back and say, "I can't do it. Can we move it?" and then it can be, "Can we move it again?" It can be multiple times before we get to do a specific task, and it is how long it takes. I am doing this because it is necessary, but I will be poorly afterwards. It is easier if I have smaller meetings and it helps my daughter too. We ask for smaller meetings and it is seen as unreasonable. I cannot understand why. We offer things like Skype, because it is a phone call with a screen. I cannot see why it should be so hard to cut a big phone call with a screen down from an hour to five, 10 minutes, and have it over a couple of weeks. It is not making more effort. You are picking up the phone, pressing a button, but it is impossible.
David Blamires: Or it seems to be.

Jeanine Blamires: Where we live there are some good initiatives coming through. Airedale Hospital is doing great things with the older carers by telemedicine, where you do not have to come in, they contact you and do blood pressure through videoconferencing, but it is not available to me. I would like it to be available to me. Not all departments within hospitals understand the needs of the carer or the cared for. They can be downright rude, which I have said in my submission.

We have got to the point where we just do not stay with that department, we go back to the GP and say, "Right, where's the next hospital?" and we go to that hospital and find the ones that are kind to carers and disabled people. I cannot put my role as carer separate from disabled person, so I cannot answer your question as a carer, because I am both. If you want just a carer's view, you must ask my husband. As both, I need both of my needs looked at. I need to be looked at as mum and listened to as mum, but I also need to be listened to as that knackered woman who at times can barely move or talk. Both are the same person. I am not seen that way. I am sure some of you will get this. I am either a "poor thing" or I am a "horrible thing". I admit, sometimes I have been very angry. I was angry when the council altered my daughter's records, which is a crime. I was angry about that and I shouted. I became this terrible person, but what they did was bad and still is not redressed. In the records I am a poor person because I am ill. I cannot be both. I am this one person who has got all these bits and pieces; see me as the whole and try and make it work, please.

The other issue is my daughter is a carer too. She is autistic. She is still my carer when I am bad. When you have a household of more than one disabled person, you have a circle of carers. As that household gets older, so do the parents. My parents, who helped us tremendously, are now having difficulties, so they are part of that caring circle. My sister, who has autistic children too, is part of that caring circle. We are all propping each other up, in spite of the services that are putting barriers in place to make our life hard. That is the tough bit. I think I have gone way off what you wanted me to answer.

The Chairman: Lady Campbell is going to ask the next question. I will just tell you her interests. She is a patron of Just Fair, a patron of the National Disability Arts Collection and Archive, a founder and member of Not Dead Yet UK, recipient of a social care personal budget, disability living allowance and access to work. She was a disability rights commissioner throughout the life of the Disability Rights Commission, and a commissioner of equality and human rights on that commission for three years.

Q172 Baroness Campbell of Surbiton: My question is to Ms Holzhausen. Hello, Emily, it has been a long time. There are two questions I want to ask—the first one because I did not get an opportunity to ask earlier. Do you have any figures of how many carers are discriminated against in employment due to their caring responsibilities?

Emily Holzhausen: We do not have any figures. That is a really good question. They are not collected centrally, so it is very hard to tell. Could I come back to you when I see what sort of evidence we have within our surveys?

Baroness Campbell of Surbiton: That would be great.

Emily Holzhausen: I will see what might be reliable. I would say the right to request flexible working that has been brought in has loosened up a few attitudes to different work patterns, but there are some more entrenched issues. For example, people think flexible work patterns is working different shifts, but for some families having set shifts—because you are a carer, because the person who comes in and supports your family in the meantime only comes in at a particular time—is what you need. Could I come back to the Committee with that?

Baroness Campbell of Surbiton: Any indication on that would be really helpful.
Emily Holzhausen: Of course.
Baroness Campbell of Surbiton: The question I am down to ask is very much about the research that you carried out in Carers Week looking at carer-friendly communities. In your report you talked a lot about the problems with the lack of carer-friendly public space and services. Would this be addressed if existing accessibility and reasonable adjustment requirements under the Equality Act were met, or is more needed in your view?
Emily Holzhausen: We would go a long way if the provisions for disabled people were implemented. A lot of the comments made by carers are made as family, as friends, who want to go out together, go to cafés, who want the person with the disability to be able to travel on their own safely, independently. That said, some of the issues we have talked about—getting GP appointments, not being carer friendly—are because the care service does not come in to sit with your husband and make sure he is safe and well. You cannot take him with you because he has dementia and gets very disturbed and upset, so you cannot get access to healthcare. Those sorts of things still exist for carers, because they do not see the disability behind the person who is a carer, just as they do not often see the carer behind the disabled person. Not every disabled person has a carer, of course, but there is that second bit that needs to be addressed.
The primary issue of the harassment and victimisation is often due to people not understanding disability, or having misconceptions about it. Another carer was talking about the private rented sector. She has a child with special needs, and was asked several times whether he was destructive or would burn the house down. That is clearly discrimination by association, but it is also directly discriminating against her child and the knowledge of disability.
Q173 Baroness Campbell of Surbiton: Some 45% of your respondents said that the high street was the most unfriendly place going. Why is this? Why do you think the percentage is so high?
Emily Holzhausen: That result was more of a surprise. You never quite know what you will get from people when you ask them, and it was a big surprise. I think it is a combination of things, judging from people's comments. It is everything from parking to people who are semi-ambulant but not wheelchair users, and distances are an issue. It is physical accessibility of getting into shops and then how you are treated in the shops and services by the staff. It is a consumer journey, if you like. I think that is where we can make an everyday difference by making changes in what we do in our communities locally.
Baroness Campbell of Surbiton: Was the availability of taxis mentioned very often in the responses to this survey?
Emily Holzhausen: Yes, availability of taxis did come up. You can also ask David and Jeanine about taxis as well.
Baroness Campbell of Surbiton: We know about taxis. I am interested.
Emily Holzhausen: The availability and accessibility of taxis did come up.
Baroness Campbell of Surbiton: Was it a recurring theme?
Emily Holzhausen: Yes, particularly when you are a wheelchair user. Not all the responses were by wheelchair users, but people who perhaps find different interactions more complicated or challenging.
David Blamires: If I could jump in on the point Emily was making that Baroness Campbell was drawing from. In one of the towns local to us, taxis charge more for disabled people. That is in Keighley. Considering you are folding your wheelchair up and putting it in for them,

I do not understand why. Apparently, just because you have a wheelchair in the taxi, that costs you more money.

Baroness Campbell of Surbiton: This has been a recurring theme.

David Blamires: I suspect it will be.

The Chairman: Can I thank you all very much for making the effort to come? I think I speak for the whole Committee in saying we greatly admire the way you are coping and standing up for yourselves and others. You have really helped us have an insight into the difficulties that disabled people face. We are very, very grateful to you. We wish you all the best. We will do whatever we can for you in our report. Thank you very much indeed.

Jeanine Blamires: Can I ask one question? Is this liable to make change?

Baroness Campbell of Surbiton: We hope so.

The Chairman: We are going to report about a whole range of issues and will do our best to persuade this Government—or another Government if it drags on—to change the law as required. We want to get a change in attitudes as well. We want employers and service providers to understand. As one of you said, the battle against discrimination has gradually been won by other minorities and it is time that battle was won by disabled people too. It is a question of changing attitudes, getting information across two ways, as you said, Mrs Blamires. We do understand all of that. I cannot promise, but we will do our very best within our constraints. We are absolutely persuaded of what you have told us, have no doubt about that.

Jeanine Blamires: Thank you.

The Chairman: I am sorry I have to shoot out, but I do appreciate your coming. Thank you very much.

David Blamires: Thank you for inviting us. We greatly appreciate the honour.