



Public Services Committee

Uncorrected oral evidence: One-off public evidence session with service users on the government response to the committee's first report, *A Critical Juncture for Public Services: Lessons from COVID-19*

Thursday 10 June 2021

10 am

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Members present: Baroness Armstrong of Hill Top (The Chair); Lord Bichard; Lord Bourne of Aberystwyth; Lord Davies of Gower; Lord Filkin; Lord Hunt of Kings Heath; Baroness Pinnock; Baroness Pitkeathley; Baroness Tyler of Enfield; Baroness Wyld; Lord Young of Cookham.

Evidence Session No. 1

Virtual Proceeding

Questions 1 - 5

Witnesses

[I](#): Debra Baxter; Dawn Knight.

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Examination of witnesses

Debra Baxter and Dawn Knight.

The Chair: Good morning, everyone, and welcome to this special session of the Public Services Select Committee in the House of Lords. We are talking today with people who have been using public services, and who talked to us when we did our first inquiry into how public services were coping and responding during the early months of the pandemic. Today, we want to listen to and engage with those people we talked to then, almost a year on, about what their experiences have been.

I am very pleased to welcome, in our first session, two people who came to us from Healthwatch, Debra Baxter and Dawn Knight. Welcome again. It is good to see you both. I will ask my colleague, Phil Hunt—Lord Hunt—to lead the questioning on this. This is not about difficult questions; it is so that we can learn from your experiences.

Q1 Lord Hunt of Kings Heath: Deborah and Dawn, a very warm welcome this morning. Can I add my thanks to those of Hilary for you joining us today? I would like to start by asking you how things have been for you over the last 12 months. What have been the good things, the challenges, the support you have had from public or voluntary services? How have things been?

Debra Baxter: Can I first clarify that, when you say “public services”, you are combining the NHS and social services into one? They are two completely different organisations with completely different ethics and ethos, which could make the delivery of services totally different. The NHS has values of teaching and learning. Social services have an ethos of believing that they know better how to do it. This is really important.

The behaviour of the people who work in these services is very important. That determines the delivery of these services. In my experience over this last 12 months, the NHS side has been great, especially the wheelchair service in my area, which I have a great respect for. They have assisted me in getting the help that I have so desperately needed. The NHS is eager to learn and this will improve with time, hopefully.

However, the social services side, in my very strong, experienced opinion, is not fit for purpose. They have let me personally down very badly, to the extent of putting my life in danger, all because their behaviour towards people with disabilities is not only ignorant but arrogant, and I would go so far as to say illegal. I was looking into taking legal action, but unfortunately this has become unaffordable for me. I am in a desperate position now to try to save my own life.

Despite having overwhelming medical evidence of my need for more support, they are trying to reduce my care support, even when I have had cancer treatment. Basically, there are no-trust issues now with the social services, as far as I am concerned. That has even been exacerbated by the fact that, when I wanted a review and I wanted to

record a meeting, they refused to have this meeting recorded. In my strong, professional opinion, anybody who does not want a meeting recorded has no leg to stand on, as far as being trustworthy is concerned.

It has got to the stage now where I am in a limbo situation. I cannot have a review and that means I cannot get my support needs sorted. Every day, I have to make a judgment call on how many drinks I have, so that I can transfer safely to go to the toilet. Even just showering, with the limited support I have, deteriorates my energy levels to exhaustion. I have had medical evidence telling me that I need to save my energy as much as possible.

At the end of the day, this behaviour from the social services shows that they are the total opposite of the NHS. I do not trust them to do an assessment of my support needs. That is basically where we are up to now. We are in limbo and I am in a very serious situation, where I could fall and it could get life threatening, but they are just not willing to make compromises and record any meetings. This last week, they have even threatened to close my case. I have had to send a very strongly worded letter, which I have had no response to at all. I feel very alone here and very mistrusted. It is very upsetting.

Lord Hunt of Kings Heath: Thank you very much for sharing that with us. It is a very powerful testimony that you have given. It was good to hear about the NHS and the wheelchair service. Can I ask you about social care? Have you had any help in order to make your case to social care, or any support in advocating on your behalf?

Debra Baxter: No. I am very good at knowing what my rights are. In my area, I am esteemed for being able to advocate for myself and for other people. I am very trained up in advocacy and disabled rights. If anybody knows what my rights are, it is me. Now, the social services are not even respecting me as a professional. What is really disturbing is the fact that they know that I am an equality specialist, because I work in other departments in the council and with the NHS as an equality specialist. They know that I know what is right and are still basically trying to prevent me having more support, even though the medical evidence is backing me up.

Unfortunately, we are talking about the voluntary service. Actually, I am the voluntary service. I am the one who goes out and helps other people, yet they are not trusting me with the values and expertise that I have. I would not lie. I have built my reputation on the fact that I always tell the truth. They know this and are still trying to prevent me getting more support, which I need.

Lord Hunt of Kings Heath: I do not think anyone could be in any doubt about the power of your advocacy, which has come through loud and clear this morning. I was hoping that you were not alone in this.

Debra Baxter: I am alone. I am feeling very, very alone.

Lord Hunt of Kings Heath: You have made that point, yes. We will come back to the issues this raises. Could I turn to Dawn to perhaps talk about her experience over the last year?

Dawn Knight: I spoke to you last time as a carer for my husband, and you can probably tell that my answers will be that things have got worse because of coronavirus and the pressure on services. For example, last year, Paul, my husband, had what is called a spirometry test in a hospital in Bristol. That was in August and we still do not have the results. We are finding that GPs, although they are under tremendous pressure and there are not enough of them to deal with the population they have, are having to chase up test results, other consultants and other departments, when they do not have the time to do so. That has left my husband vulnerable, still with breathing problems. We have had tests, but we cannot get any further. That is one example.

Paul, my husband, went into hospital a couple of months ago, with an episode of what I would call paralysis. Unfortunately, they thought my husband was playing the mental health card. Mental health stigma is alive and well. They treated him differently, I think, because his notes would have said that last year he felt suicidal. With the symptoms that he went in with and the test results he had, my GP said that he should have had a scan and seen a neurologist. At the time, I could not go in because of the coronavirus restrictions.

When he came home, he was distraught, because of the way he had been treated. I complained and rang up the hospital. It was lucky that I did, because the next week I had a phone call from a consultant, saying that they got it wrong and they were going to send Paul for a scan. If you do not have a carer or somebody who can stick up for and support you, you are on your own. That has been our experience recently.

Going back to the GP I was talking about earlier, with GPs being gatekeepers to all services, they seem to be in a really difficult position. The GP is the first point of contact for everything. They need more resources. They need more admin. They need more time to deal with people. We are very lucky; we have an excellent GP, but I hear how many are leaving every day and how many spaces there are for GPs. For example, in Weston-Super-Mare, which is not far from me, there are some GP surgeries with hardly any GPs. They will deal with you only if it is an emergency. This is not fair on GPs or the admin staff at the GP's. The NHS really is on its knees at the moment.

Lord Hunt of Kings Heath: Thank you for sharing that. Clearly it has been a very tough year for you. Can I ask about your GP? You clearly have been able to get access to the GP. Has your GP been able to get to the bottom of why, for instance, tests have taken so long to come through?

Dawn Knight: I do not think so. I have chased the results. I am a mental health nurse and I have been a carer for a long time. I know the system now and how to chase up results. I have tried and failed. I have

rung the hospital where the tests were done and the hospital where we spoke to a lung doctor, and I cannot get anywhere. It is really difficult.

Lord Hunt of Kings Heath: You clearly know your way round the system. Have you been able to get any help from anyone who could advocate on your behalf?

Dawn Knight: This leads me into the answers I had written down for another question about the voluntary sector.

Q2 **Lord Hunt of Kings Heath:** Do you want to come on to that? I will come back to Debra too about that, then open up to my colleagues. It would be great if you could talk a little bit about the voluntary sector.

Dawn Knight: In the past, we have used a service in Nailsea, which is in north Somerset, called the Nailsea Disability Initiative. As far as I know, it is all run by volunteers, who are brilliant. They have really good knowledge of the benefits system. They have helped us with benefits and reviews. Last year, we were midway through a personal independence payment review for my husband, and all that closed down because of Covid. If they had the expertise and resources, maybe they could have helped people, as we are now, over Zoom or some sort of digital platform, but that has not been the case. They seem to have closed down completely.

I had more work to do. I had to appeal the PIP review myself, with limited knowledge. I do not really know what I am doing. That came back and said we did not win, so I had to appeal the appeal. Then we were faced with going all the way to Cardiff to have an appeal meeting. Luckily for us, we won the appeal on the appeal and did not have to go to Cardiff, but it would have been quite difficult to get us both there, stand up in a court and have to give evidence. We have not had the help from the Nailsea Disability Initiative. I am sure they would have helped us if they could have.

Lord Hunt of Kings Heath: Well done on your efforts on the appeal. Debra, could you talk a little bit about the voluntary sector in your patch?

Debra Baxter: Like I said before, I am the voluntary sector. I probably know just as much as the voluntary sector. Over the last 25 years, I have volunteered in different areas of the voluntary sector. As well as working for Healthwatch as a volunteer, I also run my own peer support group, which I try to advertise as much as I can. It is all done with little or no money. I support other people and signpost them to the voluntary sector where they would need to go to get the help.

Like Dawn was saying, because of coronavirus the money is limited even further for the voluntary sector, so they do not have the resources to go and help the people they want to help. I have spent the last 12 months in my patch of the CCG and the NHS working on equality impact statements to help them roll out the vaccine programme and other projects. I have been used to this technology issue of doing Zoom, because all my meetings have been via Zoom, rather than face to face.

As I said before, Dawn is quite correct. The voluntary service funding is very poor and they are very limited. Because of the coronavirus, they cannot go out to people, which they need to do face to face, so it is either on the phone or via video link. Technology is brilliant, but unfortunately it has its limitations. At the end of the day, when you do not see somebody face to face, you do not get the whole picture that a face-to-face meeting can give you.

Coronavirus has not just prevented the voluntary sector from helping people in the way it should do. There has also been the money situation of not being able to help as many people. Because of the coronavirus, the number of people who need help has grown more and more.

Lord Hunt of Kings Heath: Thank you. Dawn, did you want to add something?

Dawn Knight: Sorry, I looked at my notes to remind me. I am menopausal, so my brain is not working very well. I just wanted to say a positive thing about the voluntary sector. I cannot remember whether I mentioned this last time I spoke to you. Paul had help, last year and this year, for about five months, with very specialist therapy from a charity called Second Step in Bristol. I wanted to mention that. That therapy has been very helpful.

I do not know if you understand not the mental health services as such but the services that deal with psychological problems in the NHS. They probably have a limited amount of therapy time that you can have. This five months was really amazing. Sometimes it needs a lot longer than the standard six or eight weeks—whatever is normally offered. That time was really needed and really valuable. In fact, Paul has recently had a follow-up from his therapist just to check things are okay. I want to say thank you; I think the Government gave Second Step some extra funding because of coronavirus, so it was very useful.

Lord Hunt of Kings Heath: That is very nice to hear.

Q3 **Baroness Wyld:** Good morning, Debra and Dawn. Thank you very much for sharing your experiences. Dawn, I wanted to ask a bit more about your experience with the hospital and that horrible experience of not getting that test result back. I know you talked about having to chase it yourself. What sort of attitude did you encounter when you contacted the hospital and asked? What did people say to you? I would be really interested to hear how it felt when you were talking and chasing.

Dawn Knight: This was the Bristol Royal Infirmary. I was ringing, I think, the spirometry department. They just said that I would have to deal with the person who referred Paul in the first place, which was the GP, so it was kind of a dead end really. Then I chased the respiratory consultant at Weston General Hospital and went through the secretary. Again, it was a bit of a dead end, to be honest.

Baroness Wyld: I am sorry to hear about it.

Q4 Lord Young of Cookham: Debra, could I go back to something that you said right at the beginning—the distinction you drew between what I might call the culture in the NHS and the culture in social care? You were very explicit about the contrast between the two. I wonder whether you have any idea what lay behind that. Presumably the people who go into social care or go into the NHS basically have the same objectives of trying to help. What do you think accounts for this differential treatment that you experienced from those two organisations, which basically are both caring organisations?

Debra Baxter: I really wanted to tell you, because I consider myself quite experienced in this. We are talking about disability discrimination here. The NHS has a culture of learning, listening and things like that. It is important to listen. Unfortunately, social services have this culture that “social services know better”. It is about them telling us what to do, rather than us telling them.

It really is about disability discrimination. I know there are laws to protect disabled people. The Disability Discrimination Act has been in force for 26 years now. The Equality Act has now been in force for over 10 years. Quite frankly, disability discrimination is really apparent in the people who actually work there. It is not always like that. I have to say that there are some very good people in different areas, but it is like Russian roulette as to who you get and what kind of behaviour they have towards you.

I find that social services have such a controlling attitude towards you. They think they know best because they are trained. Some people want to learn from experts by experience. I am sure that Dawn would agree that, when you have an expert by experience attitude towards the people you are talking to, you have a more positive outlook and a positive reaction from them. That is what I have had with the wheelchair service in my patch.

Dawn talked about not being able to get to consultants because of the backlog through the coronavirus. I have had to get support from the wheelchair service to go to another doctor, who can then get me the test that I need to prove that my disability is deteriorating very badly. I am going for that test this afternoon.

Lord Young of Cookham: Good luck with that test, and thank you very much.

Q5 Baroness Pitkeathley: Dawn, you are clearly an expert carer and working on Paul’s behalf. Has anyone offered you support, not to help you help Paul, but to help you in your role as carer? Have you had any support of that kind?

Dawn Knight: I have had a carer’s assessment this last year. It has been a bit mixed, to be honest. I have had carer’s assessments in—I do not know—the last four years, let us say. There is something called a direct payment that carers can get from the council. It is an amount of

money. It is £500 that you can use towards something that would help you carry on being a carer, as long as it is not for health needs.

In the past, I had always asked, "Could I have some money to help me with the garden?", because we have a big garden and Paul cannot help me anymore. It has always been refused. This year, I had the carer's assessment, actually by an ex-colleague who works for the council, instead of an organisation called the Care and Support Alliance, which had done the previous carer's assessments. She got me the money and they actually said that I could use it towards cleaning in the house. I now have a cleaner who is helping me, because I am disabled myself now because of long Covid. That has been a huge help.

Baroness Pitkeathley: Did you feel it was something of a fight?

Dawn Knight: In the past it has been, yes.

Baroness Pitkeathley: Did this particular person who did the assessment work the system differently?

Dawn Knight: I guess so, yes. This time, I got an assessment through the post, so, yes, it was done differently. I do not know what the problem has been previously, but it worked well this year.

Baroness Pitkeathley: Thank you very much. I hope you recover from your long Covid soon.

Debra Baxter: I am a veteran with direct payments and what Dawn was saying. I have been on direct payments for my care support since 2002, and I actually worked with the direct payments team from the council here as the expert. In fact, tomorrow I will be in a meeting to help them revamp the toolkit, in order to help the recipients make the best of their support package. This is what I am working on as a volunteer. That is why I am considered an expert on equality around disability issues.

This money that I have been using has been reduced and reduced so much that, until recently, I was struggling to find somebody to come and work for me, because you can get more for packing bananas down the road. The social care package is becoming so stretched that you cannot get people to come and work for you. It is very difficult. I know that it is all about funding and everything. I believe that, for people with disabilities who live on their own—this is what one of my colleagues has said—it is really about supporting people who need it the most.

Those who are most vulnerable are the ones who are on their own and do not have any family to support them. My colleague said that these people are targeted more. The people who are alone the most seem to be targeted more by social services and are being stripped of the support that they really desperately need. Unfortunately, this is what is going on a lot. More and more people feel more and more vulnerable, not just people like me who are disabled and on their own. My daughter lives 25 miles away and is not always available. Do you remember her from last time?

Baroness Pitkeathley: I do.

Debra Baxter: At the end of the day, there are also families like Dawn's, who are feeling left out, alone and have nowhere to go. It is a very sad situation, but I want to make things more positive. I want to tell you that people like Dawn and me are the experts and we are not being listened to. The social workers are turning round and saying, "We have the degree. We know what we are doing", and actually they have no idea. They do not respect us. They do not listen to us. It is very frustrating and annoying.

The Chair: Thank you very much to both Debra and Dawn. We could go on talking all morning with you two, but I am afraid we have others we need to move to. Thank you enormously. You have both been very open and honest. I hope that we can come back to you with ideas, in our own way and the way that we work, that will prove helpful in the future. Please do not think, "They have talked to me and that is it". Come back to us and keep in touch. If there is anything we can do, we will do it. We are enormously grateful. Your stories are very important in how we tell the story of public services and the pandemic. Thank you enormously.