HOUSE OF LORDS

Adult Social Care Committee

Corrected oral evidence: Adult social care

Monday 21 March 2022

3.45 pm

Watch the meeting

Members present: Baroness Andrews (The Chair); Baroness Barker; Lord Bradley; Baroness Campbell of Surbiton; The Lord Bishop of Carlisle; Baroness Eaton; Baroness Fraser of Craigmaddie; Baroness Jolly; Lord Laming; Lord Polak; Baroness Shephard of Northwold; Baroness Warwick of Undercliffe.

Evidence Session No. 3 Hybrid Proceeding Questions 23 - 34

Witnesses

I: Tricia Nicoll, Expert by Experience; Andy McCabe, Expert by Experience; Sue Bott CBE, Expert by Experience.

Examination of witnesses

Tricia Nicoll, Andy McCabe and Sue Bott.

Q23 **The Chair**: Good afternoon, everyone, and welcome to the third oral evidence session of the Adult Social Care Committee. We have only one apology for absence this afternoon, and that is from Baroness Goudie.

I am absolutely delighted that we have three witnesses who will be able to assist the committee, because they come from the world of lived experience. They have all had experience of drawing on adult social care, and they have important information, evidence and experience to share with us as a committee this afternoon. They are Sue Bott CBE, Andrew McCabe and Tricia Nicholl. I welcome them and thank them most warmly for making their time and their expertise available to us this afternoon.

We are at the start of an inquiry that is looking at some of the issues in adult social care that get overlooked sometimes, because there is so much activity going on in this field. We are looking at the experience of people who are often not very visible, and they are the people of course who are central to the whole idea of what adult social care is for, and what it should be like, at its best. We are looking at the experiences of people who are carers and the people they care for, whether they are young adults or frail and elderly. It is an enormous spectrum, with very diverse experiences, as you know. Our questions this afternoon and our conversation with you will be about why this group of people, who are so important when we think about adult social care, are relatively invisible.

We are very interested in identifying what needs to change to enable the delivery of social care that really can fulfil your best ambitions, and your needs, for the people like you who draw on services and on care. What should the delivery of the best sorts of social care look like? What stops this happening? Where are the barriers? How can we best address some of the barriers in the short time we have as a committee? Sue, what is your experience?

Sue Bott: My experience will be different from that of others, but it might be quite illuminating anyway, because I am entirely reliant on charity for the services that I receive. I do not get anything from the formal social care services, as it were, the statutory services. I have been visually impaired since birth. I use my trusted guide dog in everyday life, and she is absolutely essential to me.

I just want to get on and live my life like other people, and I need the assistance to be able to do that. That is what social care should be about. It is about enabling us all to fulfil our ambitions and what we want to do in everyday life, as people who do not need to use assistance services would just take for granted. That, in essence, is what we want to do.

What stands in the way is that getting on with an ordinary life is not fully understood. Unfortunately, there is still too much of a tick-box attitude to social care. Someone else is determining this, that and the other, and it is whether you tick the boxes, rather than starting with you as the person

and what you want to achieve in your everyday life. In a nutshell, I would say the barrier is not understanding that we are about living our everyday lives the best that we can.

The Chair: I love the definition you have offered us about living your life like other people. That says it all, and the way you describe the barriers as universalised but not personalised. Andy, what would be your response to that?

Andy McCabe: Similar to Sue, I have broken the thinking down on what we think social care should achieve and what it should be. At the base level, you have to keep people safe and ensure that they have dignity, but that is quite a low bar to set, and I see it failing in some instances, which is terrible to see. If we are talking about what it should actually be delivering, it needs to provide much more than that. It has to provide the ability and wraparound support that enables people to live their life, and live a life that they want to live. It is about promoting independence and giving choice and control—all the things that people take for granted.

You can talk about community and family links to build that, not as a second-best replacement for the support that should be provided but as a way of enhancing it. It is always good to see friends and things like that, but you would not necessarily rely on them for everything. To use commercial jargon, which I do not like using, it is talking about user-driven things where the person is at the centre, at the heart, of the decision-making. It is their life that you are trying to enable and empower, rather than all the other bits around it, such as funding and things like that that are difficult. It also needs to be individualised and personalised, with long-term thinking about the ability of aspiration and dreams and futures. It is not just short-term thinking about the here and now, but using the short-term thinking of the here and now to get to the longer-term dreams and aspirations.

A barrier I have experienced personally was not knowing what was available from social care. That was an initial barrier for me when I needed more support from the local authority. There was very little support from the local authority to navigate the system. I had to rely on charities and other people who were more familiar with the system. It was a chasm of the unknown. I did not know what to expect or what would be available.

Another barrier that I found was wrong and bad information being provided by the local authority. One example in my case was to pay less than the minimum wage, which would have landed me with problems if I had actually done that without getting advice from other people. Another barrier that I would like to highlight, which is not necessarily as obvious, and is more like a hidden influence and pressure, is a concern or fear that I have, which many other people in my position have, that when I contact social care because I need a review, or advice or support, my budget will be cut. Just by contacting them and them getting more involved in my life, suddenly things might start getting pulled away. That means I would

not contact social care unless there was a serious problem that I needed to deal with.

A smaller problem is how social care is set up in local authorities. For me personally, I am looking to move this year and I have already been told by charities that it might be a fight to get the same amount of funding as I get now. Even though my needs are not changing, my postcode is changing. That limits what we were talking about earlier: aspiration and just living a life.

One other barrier I have found is that the local authority needs financial contributions from me as a person, whereas if I did not require care I would not have to make those contributions, and if I was in full-time work, earning much more than I currently get, I would pay lower contributions. That financially limits my life as well, and takes away choice and control, which to me feels fundamentally wrong.

The Chair: You have just given us three examples of why the notion of invisibility is a reality.

Andy McCabe: Yes.

The Chair: If you are reluctant to approach the local authority because things might change, that is a very serious position to be in. I will let my colleagues develop that. There is a lot of extremely important information there for us. Thank you so much. Tricia, what about your experience?

Tricia Nicoll: We will be very boring and start agreeing with each other, because they are right. A bit like Sue, I am in a different position from Andy in that my personal lived experience is that I used to say I was a long-term user of mental health services, and now in my introduction I always say I am a long-time avoider, because it works better that way. That probably tells you as much as you need to know about my experience of mental health services.

I know that you are talking to families in a different session, but I also happen to be mum to two autistic adults who still live at home, so it is hard to separate those two different experiences. The key was in your question—the words aspiration and ambition. That is where we start from, that is what all of us start from in our ordinary lives, yet it is the last place that social care starts from. It is actually the opposite to where social care starts from. Nobody ever woke up and said, and I am sure Anna has said this to you before, "I really hope I get a good service today". We wake up hoping that life will be good, or we will get to do what we want to do, or that life will go the way we want it to go. We have to stop thinking about services and support, and think instead about the tools that we need to get whatever a good life would look like.

In my work I talk about a gloriously ordinary life. I started using that phrase about five years ago, but in the last couple of years it has probably become more poignant to most of us. Everybody now coming

out of a pandemic can really understand the idea of just wanting life to be a bit ordinary. Most of us just want a really ordinary life.

There is a huge barrier for certain impairment groups. Sue brought up the one about people with visual impairments. That also applies to people with other sensory impairments. It certainly applies to anybody who lives with a long-term mental health condition. Most of what I see as needed is health support. The social care support element of my mental health is rarely looked at, and I certainly would not be eligible, because I have the misfortune of being able mostly to hold down a job, or work. If my life was in a really bad place, it might work that way.

I think it has to do with what does not work. If you compare social care to the NHS, we all think we know what the NHS does. Every person has lived experience, even if it is just going to their GP. The thing about the NHS is that it is very transactional. Even if it is positive like having a baby, it is still transactional. You want some support, you want this, you want that; it is an exchange, and you get a result. We try to apply the same principle to social care. If you think about health, you go to the GP, you have a problem, you get a prescription, or you get a referral, or whatever. We try to apply the same principle to social care: "We have identified that you've got a problem, so here's a bunch of stuff we could do for you. Right, you could have a day service place, or you can have some visits a day", but nobody has the conversation about what would really enable you to keep living the life you want to live.

When I was younger and my mental ill-health was often a lot more acute, I knew what would help me. I knew that acupuncture would help. I knew that going to the gym would help. I knew that getting to the coast and going for a really long walk on the beach would help. All those things would really enable me to stay well, but the social care support when I was at my most ill ran to a day service. That was it. That was the offer. If you think about the cost of the day service, which we know these days is between £50 and £70 a day, if you had looked at that and enabled me to have a weekend at the coast, it would have been cheaper and far more effective, but we do not see it that way. It is almost as if the medicine has to taste bad to be good. We do not like the concept of somebody having something that would help them get a good life. Everyone says, "Hold on a second. I want to go to the coast as well. Why should they be allowed to do that?" Does that make sense?

The Chair: It makes perfect sense, and it raises a whole set of issues about social prescribing. Again, we are casting social prescribing in the context of the NHS but not necessarily adult social care. I have many questions I would love to follow up, but I will hand over to my colleagues, who are longing to ask you further questions.

Q24 **Baroness Shephard of Northwold:** So far, all three witnesses have answered in their different ways the question that you asked me to ask, Chair, which is why the invisibility of social care is such an issue. Why is it invisible? All three witnesses have already, I think, answered that in their own way and, in particular, Tricia, thank you so much for being

here, and for such a colourful explanation, which was riveting. Could you expand it a bit?

One of the most interesting things you said was that you do not really want to choose from a list of things. You just want the tools to live a normal and ordinary life. A lot of people who provide social care think that is what they are doing. Absolutely no disrespect to them, but sometimes the systems and the mechanics and setting things in place blind them to the individual. One of the reasons why that is so is because there is constant underfunding and, in particular, a lack of consistency and continuity, which Andy pointed out and which particularly struck me.

I have to ask the question on this paper; otherwise, the Chair will be furious. We have heard from day one that one of the fundamental challenges of adult social care is that it is invisible. Obviously, you agree with that, or in some form you agree with that, because you have told us so. What are the consequences of it on the provision of adult social care? You have already said something about your experience of care and support services. Tricia, do you want to enlarge on that, or indeed, would the other two witnesses like to add something to what you have to say, sort of repeating but more so? Have I given you an impossible task?

Tricia Nicoll: It is more dangerous than invisibility, I am afraid. I think it is that people think that they know what it is but that it happens to other people. My family and friends who are not part of my world do not have that concept. They think, "If we're lucky, we'll get older and might need some support", but if other stuff happens to us along the way in life, there is every chance that any of us might need social care support.

There is that, and there is also something about how we see older and disabled people and what their—I am using that word intentionally because it is a form of othering—lives are like. Those people who need social care support are not like me and you. The day centre is fine, or the four visits from someone who has 15 minutes a day to come in and sort you out is fine. It is fine that you should have to rely on a charity to enable you to have a dog that enables you to get out and live your life, Sue. It is the misinformation. That stuff is seen as fine because it is not something that might happen to me. I think it is more dangerous than invisibility. It is actually a complete misunderstanding.

The things people see are social workers taking people's children away, or not taking them away quickly enough, and then it is about the older people, all the imagery around people, their arms around them and their heads on one side and "Isn't it lovely?" When I think of my feisty mother who died at 91 at home, or in our home because she lived with me until she died, that was nowhere near the image that she would have appreciated at all.

Baroness Shephard of Northwold: Thank you very much. Would the other witnesses like to add to that? I think I am beginning to be able to define to myself part of the problem. We all experience the NHS. We know what it is, or we think we know what it is, just by being born. Do you want to add something? Do you have any ideas that you think could

improve the services, not so much that are on offer, but the way they are offered, or the way they are created in order to be offered? Do you see what I mean? You are given a range, and none of those fits. How can the care services improve that sort of performance?

Sue Bott: Yes, it is very interesting thinking about the consequences of invisibility. We are not a very good lobbying group, those of us who need to use social care. One of the problems is that you need to be a good lobbying group to unlock the resources that are there. Of course, just by the very nature that you need additional support every day you are not really in much of a lobbying position, compared with other people. That means that social care misses out.

As to what you do with it, I would like to abandon all the forms. I do not like forms anyway. This is my ideal world and I would start with the person. It would just be so nice if you went and asked the person, "What are you hoping to achieve, and what would help you to get there?"—two really simple questions. We do not need all this, "Tick here", and, "Tick there".

Unfortunately, because of the lack of public understanding, there is always uproar if people think that public money is not being spent in a way they think it ought to be spent. Years ago, a couple of friends of mine—it was notorious; it was in all the papers—had some social care support. He wanted to see the football on a Saturday afternoon. He was quite happy to pay for his own season ticket and everything, but he needed assistance to get to the football, so social care funding was used to pay for a season ticket for an assistant so that he could go.

It was a great thing to do. It enhanced his life and made him feel better. I do not know how well the team did—that is another question—but it helped him and his wife. It gave her some respite every Saturday afternoon. She knew he was safe and she could get on with other things that she needed to do for herself. It was a win-win all round. My goodness, the papers had a field day and were really critical. Somehow we have to get over that. I suppose we have to ask the general public: "If something happened to you, what would you want in your everyday life?"

The Chair: Yes indeed.

Andy McCabe: On the point about visibility, I think there is public perception, which is one avenue, professional visibility and knowledge, and then the professional reality. The public perception echoes what Tricia said. People I talk to have very limited knowledge about disability and think that the system works, that everyone gets what they need and no one is left without, and that if you need something, social care provides it in the way the NHS will provide an operation if you need it. We know, as people who have experienced it, that there are often hard-fought battles just to get basic support.

The second bit is professional visibility and knowledge. I trained as a social worker. In the course that I did, adult social care was not the main priority. It was talked about, but it could definitely be done much more. At ground level you need to think about restructuring the educational side of things for social workers.

Thirdly, there is the actual professional reality, which is talking with social workers and doing some practice myself, and knowing social workers in many different avenues. Certainly, in adult social care, there is a view that they have become checklist completers and box-tickers. I know many social workers who have a creative thrust and social justice, but they are frustrated because they cannot actually use their skills. They are trained to be creative problem solvers, but then they are focused on budgets and administering budgets.

This is something that social workers themselves want to change. They want to be able to use their skills, and support people in a progressive and empowering way. I think the system is failing them as well, to be able to practise and make the difference that they want to make.

The Chair: That is a wonderful avenue for us to explore, and what you have been saying about the need to negotiate adult social care in a way that you do not negotiate the health service. There is a lot of rich stuff there. Thank you so much.

Q25 **Lord Laming:** I have two very quick questions, if I may. The people who have come to help us today have raised many questions, as you said, Chair. To go back to Tricia, I think all of us were rather taken by your statement, "I was a user of services, but I am now an avoider". Could you say a little more about that, please? Tell me why you have reached that conclusion.

Tricia Nicoll: I appreciate that, in a world of mental health, it is much more health led. Services are rarely able to support me in a way that makes any sense for me. I have some very specific needs. I have a lot of expertise around my own mental health now. I am old enough to have learned how to manage things, so I need some specific expertise. From a psychiatrist, I need specific expertise. Generally speaking, that is not what is on offer. I am not seen as someone who is expert in me. That is the real bottom line, and it applies to everybody, whatever impairment or long-term condition they live with. There is lack of understanding.

I cannot remember the maths any more, but it is however many thousand hours there are in a year, and at best I would see somebody for an hour twice a month, and probably more like once a month. Maths is not my strong point, but there are something like 8,000 hours a year, and I get about 24 hours of those for support from a professional. The rest of the time I am doing it myself with people who love me.

Lord Laming: Tricia, is it because the services do not listen to you and recognise your expertise about your own needs, or is it because what they have to offer does not address your needs?

Tricia Nicoll: It is both. The starting point is that they do not listen. They do not see me as somebody who has the expertise or, if they do—this comes on to the co-production question—they want to hand it all over to me: "You just go and sort it out". They do not listen, and they do not respect my expertise. I actually become quite a nuisance. They see me as a nuisance. I am a proud nuisance.

What they have on offer is the Blue Peter "Here's one I prepared earlier". You are like, "Oh, okay, that's not really what I fancy". When I was younger, when I really could have done with a lot more support because I was very isolated, I spent a long time in hospital. I came out of hospital, and, as I said, the offer was a day service. In our world, they are known as "day-wasting centres", because that is the level of excitement in what they might look like. I was a woman who had worked as a teacher. I was a professional. What I wanted was support to get my life back, but what they could offer me was just that. Yes, to both your questions.

Q26 **Lord Laming:** We are trying to get an understanding of what language does in facilitating or putting people off. All of us were rather touched by your statement, "I really struggled to be seen as an unpaid carer when I am a mum". Could you explain what the language does?

Tricia Nicoll: This is a bit of a passion and a soapbox of mine. Many people here know this. Language is incredibly powerful. The example I always use when I am trying to explain this to people is some of the imagery and language that was used around the end of the 1930s in eugenic Germany. There was a poster where people talked about a person as "crippled with deficits" and about "costs to the state". There was a lot of very powerful language that persuaded people that the eugenics movement was a viable and good option.

The same applies when you look at the word "carer" and think about the difference between the words "care" and "support". Care is a very passive word. I always say that I do not care for anybody. I care about a lot of people, but I do not care for anybody. It is the idea of being a passive recipient of something. A lot of the language we use about social care is very power laden. We talk about service users. We talk about clients. All those words imply that I have something to give you that you need. It is a power-driven exercise.

We also use a lot of militaristic language. We use the word "cohort". We use words that we do not use in everyday settings. Once you do that, it dehumanises and others people. Once you other people, it becomes very easy to do things to them that you would not expect or welcome for yourself or someone you loved.

Lord Laming: Thank you very much indeed. That is most helpful.

The Chair: Thank you so much. It is wonderful stuff.

Q27 **Baroness Barker:** Sue, I want to start by predicating my question on a belief that what older people with degenerative conditions need from social care and what younger people of working age need from social care

is very different. That is something that I have thought for a very long time, having done a lot of work with older people and watched the growth of the in-control movement.

The provision of health and social care in this country is built on the assumption that people have family—if they are young people they will have parents, and if they are older people they will have children—who will provide care, advocacy and support for them on an unpaid basis. Do you agree with that? Do you think that is problematic or not? If so, how do you think that determines what happens to older people and younger people of working age who need social care?

Sue Bott: Yes, I agree with you that there is an assumption that those support systems are there. I suspect that is another reason why social care does not get all the resources it needs. There is an assumption that there is somebody in the background picking up the pieces: a family member or some such. It is problematic.

First of all, it is problematic because not all of us have those family networks. To take my own case, for example, I live on my own. Unfortunately, or fortunately as they might see it—I do not know—my daughter lives in Canada and my son lives in the United States. I cannot call on them to help me at all. Luckily for me, I am a very active individual in my community. I am involved in a lot of groups. I have a lot of friends locally.

This brings me to my second point. You want to have an ordinary relationship with your friends and the people in your network. You do not want a relationship where there is an expectation that they will come along and help you do things. That is not to say that people would not do that, but you want the kind of relationship that everyone has with their friends. You do not want them to feel that you are only friends with them so that they can come and help you on the occasion that you need help. It is what a lot of married people say about their spouse; they want an ordinary relationship, not that the spouse will do the caring and paper over the cracks.

I think there can be lots of forms of support and more could be done. We should not think of people as having to rely on family, friends and networks of support. We should be a bit more organised about it. For example, I chair a circle of support for a man in Walsall. There are four of us in the circle of support. We are all people whom he has come into contact with in the past for one reason or another in his life. We meet regularly and talk through things that he wants to talk through. A circle of support works really well. There is no assumption behind it. We enjoy meeting him. We enjoy talking to him. There is an equal relationship between us—him and his friends. There are a lot of voluntary groups that can provide that sort of role as well.

The point, as we have said a lot this afternoon, is that it is about having choice and control. You are in control of situations and not having to rely

on family and friends. You want an ordinary relationship, but if people are there to help you out, provided it is on your terms it works really well.

Q28 **Baroness Warwick of Undercliffe:** I think the responses have been absolutely fascinating. We are really digging under some of the assumptions that inevitably we have all worked with in trying to assess what changes might be necessary. We are getting to a point where there are some very fundamental things that need to be looked at. Whether that is an area that we could actually do more than highlight, it is difficult to say. We will know a little more when we have done some more work. It is absolutely fascinating and invaluable.

I want to talk about the relationship between unpaid carers and those they care for. It is something we have heard quite a lot about. From what you have said, both are invisible. In other words, it is not just the carers and what they do that is invisible. Often, the people they care for are equally invisible, misunderstood or unknown to the people who might be able to help them. They are probably people who are perhaps willing to be more into co-production, but I do not want to talk about co-production; that is coming later.

Can those of you who have had unpaid carers reflect on whether or not what has happened to them and the way they have been treated, or the difficulties they have encountered, has affected your own experience of care and support? Tricia, I was quite intrigued by your experiences. Although you told us that you do not see yourself as a carer of your two children, none the less you are perhaps inevitably in that role to some extent. You are also yourself receiving, or would like to receive, care. Clearly, you are doing a heck of a lot of it yourself. Perhaps you could expand on the dilemmas involved in all this a little bit.

I will ask the other two witnesses as well. Andy was very keen to differentiate assistance and care. Again, we are back to words.

Tricia, would you mind kicking off and saying something about how better support for informal or unpaid carers could improve your own experience of care and support?

Tricia Nicoll: Yes. The words are really important. If we are not careful, it sounds quite transactional again. It sounds like you are either cared for or caring—I cannot even use the words—and it does not work like that.

At one point, my mum was living with me. She lived with me for the last 13 years of her life. When she first moved in, she was in her late 70s and very active. She was fantastic. She aged with me, got poorly and died in her early 90s. I was a mum. She was supporting me. It is not as neat as being one or the other. All of us know that any human relationship is reciprocal. Technically, I am a carer for my adult autistic daughter. There are times when she gives me care, if you want to use the word "care". Do you see what I am saying? It is the nuance of human relationships.

The world of social care wants to fit us into a box: "Which one are you, then?" It does not work like that. If we are made to do that, it is really dangerous. I am thinking about the people whom Sue was talking about

with the football season ticket. They are friends of several of us in this room: Karen and Gavin. Karen is the one who coined the phrase, "I don't care for anybody. I care about people". She says, "Don't be mistaking me for someone who cares". It is really important. She says, "He's my husband and sometimes I really hate him".

It is the real ordinariness of the human condition that we have to hang on to. It goes back a bit to what Sue was saying about how social services and social care relate to unpaid support. For me, the key is that support should enhance our unpaid and natural relationships. It should not get in the way of them.

That is the way I would come at it. It is not so much how we look at the role of someone who is caring for, or being cared for—that does not work for me—but how any services that anybody gets should enhance their natural relationships and enable those natural relationships to flourish and grow, to be friends, to be a partner, to be a mum or to be a daughter. That is how I see it.

Baroness Warwick of Undercliffe: Tricia, was there any moment for you when that actually came together and happened? What were the circumstances?

Tricia Nicoll: In terms of services, no, rarely. Services have rarely done that for me. I am thinking about the last few weeks of my mum's life when I was really pushing. Social care says that once you get beyond four visits a day you need residential care. We know that not to be true. We were getting to the point where my mum needed more than that support. I was doing that. I wanted to do that—I am her daughter—but I also needed to sleep, because I was trying to be a mum as well and, at some point, trying to run a business.

I was trying to explain that she was staying at home because that is what she wanted. I did the maths. I worked out the budget that we needed for someone to come and stay overnight. It was not possible. Just so you know, it was about half the price of her going into a residential care home, but the big computer said no. When it was finally agreed, with a huge amount of pushing and talking to directors and things, the last three weeks of her life worked beautifully because we managed to get that. But that was three weeks, and it could have been the last three months had the system worked. That was about the nuance of listening and trusting me to know, alongside my mum, what we needed and what would make our family life work better.

"Family life" are other words that are really important. Whatever families look like in the broadest nuance of what family looks like for all of us, and we have a wonderful range of what families look like, that is what support should enable. For me, it was a multigenerational household with a single parent trying to go to work who really wanted to do a good job of being both a mum and a daughter, and how the system could support that. The answer was: just listen to what I knew I needed, let me have the money

to organise that myself, and leave me alone. I am not sure if that is helpful or not.

Baroness Warwick of Undercliffe: Thank you, Tricia. Andy, you come from a different perspective. On the other hand, you have had some very powerful comments to make about this. What is your perception of the role of the unpaid carer and its impact on you?

Andy McCabe: I say "unpaid carer" in inverted commas, because it would be my dad and some other people in my life who are my family.

My experience unfortunately, and it will probably be a recurring theme, is that, instead of it being used to enhance and build up a life and be a supplementary good thing, it becomes something that the local authority relies on and uses as a way of cutting budgets or reducing and minimising expenditure to, in my opinion, an absolute and extreme degree. For instance, when I was 18 and I started getting more support paid for by the local authority, we were basically told that my dad needed to do much more than he was doing. He had to stop working five days a week and began working three days a week.

I understand that families work in different ways, but that seems like an awful lot of pressure to add to someone when I am an adult. Not only does he have to do a lot more support for me—he is my dad and he would do that—but it pulls out elements of his life, such as his employment and his free time, with no real support or thought about him. It is not just me in that situation; it is him as well. There is no real support from the local authority or anyone else who considers, in this instance, my dad's needs as well as mine. It definitely felt like a way of trying to reduce budgets and do a whole about-turn. That was the best part of 15 years ago.

Fifteen years later, we are thinking about me moving into a house near him or moving in with him when he is around in case there is an emergency. I have already been told by a national charity that gives me quite a lot of good advice that that could be a reason for the local authority trying to reduce my budget, which has been in place for the best part of eight years. It seems totally unbalanced and unfair to put that level of pressure on a family member who is now past his mid-70s and expect that of him. He has provided a lot of support. He is my dad and he would provide that for my siblings as well, but at this point in his life that is pushing it a little bit too far.

There is a fear factor. If I were to make some friends out of the blue to be able to give me that level of support—it is a bit more difficult at the moment with Covid and things like that, and I am not going out as much as I did—I would be almost fearful to introduce that into my life. The local authority might view it as a way of cutting back on a few extra hours because Pete round the corner might be able to pop in for a couple of hours as a friend.

Baroness Warwick of Undercliffe: Thank you very much.

Q29 **Baroness Fraser of Craigmaddie:** My question is the co-production question. Tricia, you have said a lot about othering, which is interesting in the co-production space. It reminds me of the fact that very few people with disabilities as children are ever asked what they want to be when they grow up. It is about capturing the ambition. Andy spoke about the difficulty of knowing what was there to ask for and what was there to co-produce.

Tricia, what is your understanding of co-production? Have you experienced good co-production? If not, what are the barriers, and how should we go about ensuring that co-production is implemented?

Tricia Nicoll: It is another passion of mine and definitely not something I have experienced too much in my life, although I spend a lot of my working life trying to help people understand it. I will be a bit pedantic and say that we need to remember that co-production was not dreamt up in the world of health and social care. It is a massive step up from people and professionals working in partnership.

If it is of interest, it was a word first coined by Elinor Ostrom in the 1970s. She was an economist who was interested in what was happening in the 1970s and the idea of scaling up. We thought we could make more money by scaling things up and that was what she was interested in. She did a piece of research looking at the police force in Chicago and the impact of crime and policing. Police moved from small local forces where officers walked the beat to scaled-up policing and, by definition, officers had to drive around in cars. She realised, and she used the word "co-production" to describe it, that the police needed citizens to police as much as citizens needed the police to keep them safe.

It was the idea that the local police officer would walk around and notice Johnnie out in a playing field at 10 o'clock at night with other teenagers, maybe having a sneaky can of lager. He would pop over to have a chat with them. Next day, he would see his mum and say, "Mrs Smith, I saw your Johnnie the other night. Don't worry—I had a bit of a chat and it's all right. I just thought you would like to know". That is the idea of a genuine relationship where people are needed.

Tesco gets this really well. Tesco has got us understanding that what we have to do as customers is walk around the shop and pick up our own shopping. Tesco could not operate unless we did what we do. How we interpreted that in the world of social care and health was to narrow it slightly to develop the idea of working in partnership, whereas genuine co-production is when we realise that a social care system needs people who draw on social care as much as we need social care. That goes back to how we see people; it goes back to seeing what people have to offer; it goes back to seeing people as genuinely expert in their life; it goes back to seeing human beings wanting to live gloriously ordinary lives rather than being grateful for a service.

My experience is that that is not how things work. Going back 10 or 15 years when I was a lot angrier and shouted a lot more, to deal with that I

would be invited to join various committees as the mental health service user rep, I remember being asked to join a committee about mental health and housing. I said, "I've only ever lived in private housing. I don't know anything about specialist housing". I was told, "It doesn't matter. We want you along as the rep". I said, "But I don't know anything about it. Ask me to come and talk about something I know about. I bring my lived experience. Ask me about advocacy, acute in-patient care and a whole range of things, but don't ask me about something I don't know about just because I have this particular lived experience".

Generally speaking, people do not respect my expertise and find it quite irritating, or they just say, "Okay, you go and sort it out", and they are not prepared to do their bit. Imagine Tesco working in the worst possible way where they want me to do my bit in Tesco by doing my own shopping, but they do not have the price and pay systems working, there are no trolleys, they do not have half the things on the shelves, there is no one to ask and you are on your own. That is not a brilliant analogy, but it is that kind of thing. It is about genuinely saying, "We can't do this without you". In a way, social prescribing started from that perspective, but it has been lost along the way in how we have interpreted it.

Baroness Fraser of Craigmaddie: Thank you, Tricia. Andy, perhaps you could comment on this. You used the term "user-driven", which you did not like. Following Tricia's remarks, where is the trust? Who trusts whom as the expert? Is it just about trust or is it about who holds the purse strings?

Andy McCabe: You could write books about trust and power, but there is generally a lack of trust on the part of the local authority in people like me who are using services. Echoing Tricia, the idea is that basically I had to become an expert to get the care and support I need to live. You would not expect me to become a knee surgeon so that I could tell the knee surgeon how to perform the operation, but it feels like you have to do that.

For me personally, it has been one step further away from co-production in the 15 years or so that I have been using social care like this. Not only did I have to become an expert and list in all the social work-type words what I needed and how, I was told that it was still too much and that I needed less. I took that to my MP and directors and got a budget that was significantly reduced from what I thought it should have been. I was just given that and I had to live with it and deal with it. They do not want to know for another year. I have an insufficient budget and then, as Tricia says, I am almost told, "Now go and make it work".

I am not a professional and I do not get paid to do that, but I have a vested interest because I want to live a life, so there is a big interest in me getting it right. It feels in that sense that co-production does not even get off the ground, because there is no acceptance of any sort of expertise. The fact is that I know how much my care needs are and that agencies will not be able to meet them. I went to agencies and got them to sign that and say it to the local authority, but it still wanted to

proceed. That was a few years ago, but it feels that, no matter how much you show that everyone is an expert on their own life, because a computer programme or a financial person somewhere says that is too much you are left to deal with it. To me, you do not even get co-production off the ground in that climate.

The Chair: Thank you.

Q30 **Lord Polak:** I have been very moved by listening to all three witnesses. They have passion, and they are prepared to battle and fight for what they deserve. If I may say so, all three witnesses are of similar ilk in that. What happens to everybody else? What we are hearing today are the successful parts. There are so many other areas and so many people who do not have the same voices, so I worry about that. I think it was Andy who said that the biggest barrier was not knowing what was available and then navigating the system. That is overridingly what I picked up. If there is anything our committee can do to nudge that dial a little bit to allow people to know where to go and what to do, we will have done a service.

The Chair: Would you like Andy to answer the challenging question you have just put? What happens to the less articulate, less experienced and less confident? Andy, what would be your response to that?

Andy McCabe: My response is that I have seen people get their hours cut. It is not just hours and money. When you take away people's hours for support, you are taking away a part of their life. That is time when they cannot go out of the house or even read the mail; they might not even be able to get out of bed in those situations. I am in a fortunate position in that I have a family around me who support me. I literally went to university to learn social work to get a bit of knowledge from the other side, but it has been rightly pointed out that for many people it comes down to how good your social worker is, how passionate they are and their case load and funding. The case load will probably be too high and the funding too low. It is then down to a roll of the dice. It is not in the same ballpark as the NHS, where you can go from service to service and, hopefully, expect one that is decent and not be absolutely terrible.

Q31 **Lord Bradley:** First, I thank Andy, Sue and Tricia for their fascinating contributions this afternoon, which lead to so many questions that we need to address. I am particularly interested in Tricia's views about mental health, because the medical model of mental health encapsulated through the NHS does not really integrate with social care and look at mental health as a well-being element as well as a medical one.

Tricia, I was particularly struck by your observation that services should enhance natural relationships, but depressed that co-production, as Andy said, has hardly got off the ground. This is probably an impossible question. Using your expression, Tricia, how do you scale up co-production to address the issue of services enhancing natural relationships rather than being another barrier to them?

Tricia Nicoll: That is not an easy one. There is the difficulty with money and all that kind of stuff, but I think the reason why it does not work

keeps coming back to how we perceive people's lives. People think they know what a mental health service user looks like; people think they know what a wheelchair-user's life is like. We have stereotypical views. My kids are autistic. People think they know what that means, and they do not.

The major barrier to good co-production that I see in all my work around the country with local authorities in making these changes is cultural. It is when we think differently about people who draw on support and what is possible. It is about really good leadership. Where we see changes start to happen, it is always when there is good leadership that gives permission for the system to change, and gives a nudge, a great big kick, to the system to change. In the early days of personal budgets, when some key local authorities were doing some really good stuff and changing how people's lives worked, it was down to some key individuals who made that change happen throughout the system.

What I see now is a massive gap. You might have a director who is committed and some really good front-line practitioners who want to do right, and somewhere in the middle something bizarre happens. The system is like a sausage factory. The message does not get out. The practitioners at the front line working with people believe they cannot work in the way the director thinks they are working. Then we put lots and lots of crazy processes in place, such as all the forms Sue was talking about, and panels where people sit around and discuss how money should be spent in ridiculous waste-of-time ways.

It is difficult. For me, it is leadership. We all have to come back to thinking about what people want from their life—what anybody wants from their life. We have to be a little bit careful about thinking that younger people and older people want different things. Human beings essentially want the same things: they want to love and be loved and live their life in the way they want, they want to be connected and get and give support, they want some direction. That might subtly change as you get older, but we have to be a bit careful about thinking it is different. That is a bit rambly. I am sorry but it is a tough one.

Lord Bradley: Would you say that effective leadership and a clear understanding of what services need to be commissioned through co-production is a step in the right direction?

Tricia Nicoll: One hundred per cent. I give my experience of two different local authorities, which shall remain nameless. A director in one absolutely got it. I had to go to director level at one point to try to get some change in support for my daughter. The director was furious that things had happened the way they did. In another local authority, the director did not get it in the same way and it just did not happen. When a director snapped their fingers and said, "That needs to change", everything changed, but when they did not see it in the same way, it did not. It is certainly a good starting point.

The Chair: Thank you very much.

Q32 **Baroness Campbell of Surbiton:** First, I must declare my interest, as I forgot last time and the time before. I require 24-hour personal assistance, which is funded through a personal health budget. I hold different voluntary roles in charities concerned with disabilities and human rights. I am a volunteer and a good friend of one of our witnesses, Sue Bott, to whom I shall put a question. I hope you do not mind me calling you Sue.

The committee is really interested in considering the importance of the community as a source of support, with the emphasis on relying on the provision of informal and formal care. Sue, as we explore community I would like you to think back to when you were running the Shropshire centre for inclusive living. What did that actually look like? What does it look like to you? You mentioned earlier the importance of reciprocity and mutuality in your support for a man in a circle of support, so you not only receive support yourself but you give it. Can I look at the role of community and what examples you might want to give of that and what you feel about it? Is there community for most people who need a little help, care and support for 24 hours?

Sue Bott: Thank you very much, Baroness Campbell. Perhaps I may call you Jane. What are friends for? They are to ask you difficult questions.

Thank you for mentioning my Shropshire days. In our centre, we had a whole number of services. We were a disabled people's organisation, so we were run and controlled by disabled people. We set up those services ourselves and got some funding, eventually, from the local authority, which saw the value of those services. It was a really good example of co-production, because we came up with the ideas in the first place. Then we helped to set them up and then helped run them. Then we had an opinion on how they were being delivered.

Co-production is such a dynamic process. It involves the people who will use the services and benefit from them throughout the process from beginning to end. It is really helpful, because then we got the services we wanted. It was an excellent community and I enjoyed my time there. As you so rightly say, Jane, it was all about reciprocity and helping each other. As you know and often say, disabled people are our own best problem solvers. We are excellent at it, because we are living our life and we know what works for us.

In our community in Shropshire, we had lots of people. I used to say that we did not just employ individuals; we employed whole families, because people would come along and help out, and our services helped them out too. That is so important, and it goes back to what Tricia said about ordinary human relations. That is what it is all about. Sadly, there are people who perhaps do not know what is going on in their community and are not able to benefit from community life. That is an important aspect of what social care can offer. It is not just about, "What service are we going to try to put you into as an individual?" Social care has an essential role in being connected with communities. It is very important to be able to tell people who they are working with and what those connections are,

not from the perspective of, "We're not going to give you a service. You'll have to rely on this, that and the other", because that immediately puts people off and is not the right relationship.

I am a great believer in good old-fashioned community development. I think an essential part of the role of social care is being involved in community development, knowing what is going on in the community and being able to connect people with one another.

Baroness Campbell of Surbiton: From your experience of doing that in the very big county of Shropshire, where would you upscale it? You are aware that there are many communities that are so diverse that there is not that sense of community. What happens to people who are not connected to communities?

Sue Bott: You have to be proactive and reach out. I think that was one thing we did pretty well. You have to accept that there are people who do not know what you are doing and what is going on, so you need to reach out to those people and tell them what your community is doing and invite them to come along and be involved.

Baroness Eaton: It is very heartening to hear about the experience of the community in Shropshire. "Community" is a word we seem to have used rather a lot in some of our deliberations. I think it can mean different things to different people.

I was thinking about rural places. Do they equally have the likelihood of creating the kind of community you described, or is it likely that those kinds of opportunities arise largely in more urban areas, or more clearly defined communities in the sense of geographic communities? Are we talking about geographic communities or communities of interest? What clarity can we have in our discussions and deliberations on what is meant by community support?

There is one other thing that has absolutely nothing to do with thoughts about community. It is something Tricia said that I thought we needed to lob into the conversation. Tricia, you were talking about the times when you had to speak to the director of social services and the organisation underneath did not necessarily respond. Nobody has mentioned the role of the elected member, the local authority person in the community, and how they can relate to both the service their local authority should be providing and the relationship they can have with their community. Surely, they have a role to play in encouraging or facilitating a better service. That is just a point for later, not now, but I felt I should mention it while I thought about it. Going back to the community, I think we need clarity about what we mean each time we use the word.

Sue Bott: That will be quite a difficult one, because I suspect, and I know personally, that we all use different communities, and sometimes we use them all at the same time. As a disabled person, I like nothing better than to be with my community of disabled people, because I get so much support. I have great fun when I am with other disabled people,

but I also love my local community. By the way, I am glad you referred to local authority representatives. I am just at the humble end; I am a parish councillor.

Baroness Eaton: It is an important role.

Sue Bott: I am able to take up some things. Elected representatives are important. If we try to define community too much, we may be missing a trick, because we relate to all sorts of different communities, depending on where we are and what we want and are interested in.

The Chair: I can see that you will leave us to struggle with that, Sue. Never mind. We will have a go at it.

Q33 **The Lord Bishop of Carlisle:** Andy, I want to go back to where we began, which is the whole question of navigating the system. We have heard from you and the others very powerfully about some of the problems in navigating the system. You said you had to become an expert by going to university in order to access what was available to you.

If there was one practical change that we were to recommend that would support you and others in accessing care and the social care system, what would it be? I do not want to put words into your mouth, but from what people have been saying, I wonder whether it might have something to do with people listening and proper conversations with human beings, rather than computers and tick boxes. That may not be what you want to raise, but what one practical thing might you want us to recommend to others?

Andy McCabe: It is probably multiple things in one. What you said is fundamental in relation to human relationships not relying on pre-formed ideas, such as the Blue Peter example: "Here's one I made earlier". To get to that level, there needs to be more work with large charities, such as In Control, which was mentioned earlier, so that their knowledge can come on board. It is such an important issue that there should be investment of time and money into getting groups of people who know the systems, such as charities, social workers and people like us who use them, to create a clear road map with very clear publication of what we can expect, what is available, what people have done with budgets and how they use their care. It should be done clearly to avoid inexact and vague ideas, because I have found that the vague language adopted by local authorities is used in a way that makes something look possible, but when you try to get it, it is quite watered down. I think that would be very helpful.

In the longer term, another thing that might be helpful is to hone the role of the social worker in all this so that they can move to being more rights focused and supportive, rather than tick-boxing and all that kind of stuff. In blue-sky thinking, I can imagine independent local hubs, run by disabled people and organisations. There needs to be a level of independence from the local authority and the funding, where people

assess need and ideas for support plans and support budgets so that they are not financially led but needs led.

This could be done alongside social workers and peer workers to utilise what the community can offer, but they would be so independent that they could advocate on behalf of people like me, or people who cannot advocate for themselves, as previously mentioned, in an independent manner, driven with knowledge and passion to get the level of support that, to be very clear—I am sure everyone knows this already—is not over and above what your neighbour gets or the life they live; it is so that you can live an ordinary life and not have to worry about the world suddenly falling in because care and support is no longer there.

The Lord Bishop of Carlisle: That is tremendously helpful. Thank you very much.

The Chair: Thank you so much for that, Andy. The creation of the hub has surfaced sometimes when we have talked about Scotland, and it is a really interesting idea.

Q34 **Lord Laming:** I am sure that every member of the committee has been impressed by the struggle that each of our three witnesses has had during their lives. If you were to ask social workers about how they approach their work, they would say that users of services know best what their needs are and, therefore, they are the centre of our thinking. In contrast, the users of services we have heard from today tell a different story. Andy, could you say what you think would reconcile those two different positions, where people believe that users are at the centre but the users feel they are not being listened to?

Andy McCabe: From my perspective and from the education I have had in social work, it always begins with the person you are working with, generally. Obviously, there are different cases in child protection and things like that, but generally people are the experts in their own lives. I think this is a more theoretical idea because, once you come into practice and you have the hard realities of multiple people working with a limited budget, that power gets pulled away from the person you are working with and you have to do case management and juggling.

The fundamental pressure is financial. There will never be unlimited money, but if there was much more money, the people who are worked with and who need support would be listened to far more. That is probably the fundamental limiting issue, but even in the context of the financial issues, if social worker case loads were lower and more time was dedicated to training on planning and future ideas, and more creative thinking, it might at least move towards fostering growth. It will not come overnight. It is about building so that it improves, rather than stagnates or gets.

Baroness Jolly: I still do not think we have got quite to the bottom of what it is like to be a carer in a rural area. It is phenomenally lonely. My brother was my mum’s carer for the last five years of years of her life

and he was brilliant, but he had a 20-hour day. I turned up at weekends and took over, so he cleared off and I then discovered exactly what it was like. There was a support group for carers, but the funding was pulled. Most people drove at least 15 miles to get to the group in the first place, and thoroughly enjoyed it.

We have heard before that local authorities are not thinking about the carer; they are thinking about the person who is being cared for. That might well be what they should be doing, but is there a need for someone to visit, not inspect, and to support unpaid carers, whether they are family carers or friends, on a regular but not frequent basis, to ensure that somebody can be objective about the person they are caring for, and to see that all is well with them and with the carer too, because a lot of them feel they are just thrown to the wolves?

Tricia Nicoll: That is really hard. It is not quite how I see it. I would not be the person going to a carers' group.

Baroness Jolly: My brother was living with just mum and the distances were silly.

Tricia Nicoll: I understand rurality. Before my mother lived with me she lived in a rural community in the south-west, and I was often the support there. It is different. Rurality is definitely an issue, but I struggle with the idea of rurality being an issue, rather than it being perhaps different for unpaid support. If social care support really supports the family unit in the broadest sense of the word, your issues will be dealt with. Does that make sense?

Rurality is a wholly different set of things. Distance is involved, as is isolation. That is true, but for me it is much more about whether the system of support considers family. There were times when there was always a separate social worker for my mum and a separate one for my daughter, and never the twain shall meet. I was in the middle saying, "Hello, I'm the family here". It is the idea of respecting and thinking about family, and then the things you are talking about will be covered. Your brother would not have been in that situation because someone would have spotted that it was not working.

The Chair: Thank you very much indeed. We have come to the end of the session, and we are all rather reluctant to let you go because you have been wonderful witnesses, if I may use that term; we are struggling with language in all sorts of ways. It has been a privilege to hear of your experience and to have the clarity with which you have presented so much and the language you have used to challenge us. You have challenged us in many different ways this afternoon to look at things differently. If we could translate that and use those lenses, we would be doing something useful, and even significant. You have given us your knowledge and passion; it has come through in everything you said. It is so much to do with family relationships. You have put language and meaning around the fundamental questions you have raised, so we are extremely grateful to you. I am sure that this will not be the last time we

engage with you.

Thank you, Tricia, thank you, Andy, and thank you, Sue for everything you have shared with us this afternoon and for illuminating so much that is very hard for us to understand, unless we are allowed to share it with you, and enabled to share it with you. Thank you very much indeed on behalf of everyone. Thanks to my colleagues for their excellent questions.