HOUSE OF LORDS

Adult Social Care Committee

Corrected oral evidence: Adult social care

Monday 27 June 2022

4.40 pm

Watch the meeting

Members present: Baroness Andrews (The Chair); Baroness Barker; Lord Bradley; The Lord Bishop of Carlisle; Baroness Eaton; Baroness Goudie; Baroness Jolly; Lord Laming; Baroness Shephard of Northwold.

Evidence Session No. 19 Heard in Public Questions 142 - 148

Witnesses

I: Andy McCabe, expert by experience; Tricia Nicoll, expert by experience.

Examination of witnesses

Andy McCabe and Tricia Nicoll.

Q142 **The Chair:** We turn now to people with direct experience of care. I am delighted that we have Andy McCabe and Tricia Nicoll back with us this afternoon. Again, thank you both for your time and commitment to our work. Without you, we would not be making much sense, so I am very pleased to see you again.

I shall kick off with a question to Tricia. We have all been very struck by the huge gap between this deficit model of adult social care and the rights that people have to go on and live lives that are as full and fulfilling as possible, as we all want to, and to make the contribution that they can. We have been looking at some of the other models available. There are not very many of them and they are not universal, but they are strength-based and asset-based approaches. For example, we discovered local area co-ordination in Somerset, the Wigan Deal, the best practice that Wigan has come up with, which is a very clear and co-ordinated system, and the work that Shropshire Council is doing.

Are those examples familiar to you? Do they resonate with you? Would you like to see that sort of thing replicated in different parts of the country and local areas or do you know of other examples that are equally good and could also be scaled up? We are in the business of trying to find things that can work not only in the places where they work now but in other places. That is to Tricia, but, in fact, if Andy has a comment, I would love to hear from him as well.

Tricia Nicoll: Thank you so much. It is really good to be back. It is a bit of a segue for me between the previous session and our session because I have lived experience of directly getting support myself, but I am also mum to two young autistic people and, interestingly, someone who would not describe themselves as a carer.

The Chair: Yes, I remember our conversation.

Tricia Nicoll: Yes, so that is interesting. I am very familiar with all the examples you are talking about; they are all really good examples. What it comes back down to, and this is why I do not describe myself as a carer, is that they are fundamentally about the attitude and thinking we have around older and disabled people, and anybody who needs to draw on social care support. All that the examples you have given—jargony words such as "asset-based thinking"—mean is that we are interested in thinking about anybody who happens to be older or disabled and who needs to draw on social care support as human beings with the same wants, needs and desires for living a great life as we all have in this room. That is all those approaches are.

You can give it a name. You can call it the Wigan Deal or local area co-ordination, but it is fundamentally a cultural change. If we think about people as passively needing to be cared for, it is really hard to think about them as someone who is a partner, a lover, a mother, a brother, a

business owner, an employee, someone who likes to go down the pub on a Friday night or who wants to go to Australia on holiday. For me, all those approaches that we talk about—they are approaches; you are right—massively change how we think about older and disabled people.

Right at the beginning of the session, you talked about how we have the best policy we have ever had currently. There is nothing in the policy that prevents everybody having decent lives but, somehow, it is not happening. The same could be the case if we said that everywhere had to do local area co-ordination. People would find a way of making local area co-ordination work in a way that did not actually change how we think about people. I am going to be a bit of a broken record this afternoon. For me, it has to be about how society thinks about people who need to draw on social care support to live their best life.

The Chair: How do we change people's thinking? Katy talked about leadership. We have been talking about a Carers' Champion, for example. Is that too glib a solution?

Tricia Nicoll: For me, people have to be visible. Older and disabled people have to be visible in ordinary, everyday places, and we have to stop thinking about going to social care as a disaster. Social care is an enabler. Whatever you call it, it is an enabler for me and my kids to live a really great life. That is why I struggle with the whole carer identity. Being cared for is a horrible concept; I do not know if anybody here would want to be seen as someone who was cared for. You would want to be cared about, yes, absolutely, but "cared for" puts you in a very passive role.

While we still use that language, it is difficult to change how we and the general public think about social care. I get it. It is hard to believe, but I used to have very short peroxide blonde hair and, where I lived in East Yorkshire, they called me "The Angel", apparently, because I was this amazing person who looked after these two poor children. That is how I was seen. That was the thing. My kids are a bit different. They are a bit odd. They do things differently. In the village I lived in, that is how they saw me, as this amazing woman who had sacrificed her life. It is complete rubbish. We still think like that.

In response to your question about "how"—if Baroness Campbell were here, she would be smiling at me—we have to remember that older and disabled people need to be in paid roles, through disabled people's user-led organisations offering the support. That is where the support comes from. It comes from people who have been there and done that. If you want a plumber, you ask your friend who you know has recently had a plumber because they know, so it is exactly the same principle.

I was working with Baroness Campbell 14 years ago on the Health and Social Care (Independent Living) Bill. There was going to be a disabled people's user-led organisation in every single local authority area. There just is not any more. That funding was there and is no longer there. They

are being decimated and, until we have that infrastructure, I do not see how we can make that work.

The Chair: Where did that funding come from and when did it go? Who funded them?

Tricia Nicoll: From my memory, it was some central government funding that came out to local authorities, which had to look at how they set up disabled people's user-led organisations. There was a very brief spell of time when they were growing and developing. What went wrong was that they started getting incredibly controlled in how they were commissioned and the hoops they had to jump through, because of the procurement processes we have in local authorities, which are enough to send anybody completely daft. Andy is nodding, so I must be right.

Nobody is able to hand over money and say, "You guys know what you're doing. Can we agree some outcomes? Spend the money how you think it should be spent." They just do not. I used to run a user-led organisation. They tightened the hold and made us jump through hoops.

The Chair: Thank you so much, Tricia. I am just thinking about whether the ICBs (integrated Health Boards) would be useful to us. We might come back to that. Do you have anything to say on this question, Andy?

Andy McCabe: I would echo what Tricia said. You can almost flip on the head some of the approaches, such as strength-based approaches, and they can be quite negative because, if you focus on people's strengths, you can minimise the support required. That is a dangerous route to go down in the sense that, on the face of it, it is almost really empowering. Actually, it is just used as a method of withdrawing support from people.

At university and doing social work, what we want and what we should be aiming for is to enable people to live the life that they want to live, regardless of the labels that you attach to that, very much as Tricia said. How do we get to that? It needs to come from a place of empowerment and respect for lived experience. It is as simple as that if you want it to be.

The Chair: We have quoted the examples that we have access to. Do you have other examples where you have had empowerment to better effect at local authority level? Sorry, I will stop asking questions in a moment, but I did want to capture this.

Andy McCabe: It is down to individual workers. I have found that, if you get a very good worker who understands the system and can explain your rights to you, you get much further than with someone who is not interested. I have had both, and I can tell you the difference is absolutely gigantic depending on the quality of worker.

The Chair: Yes, I am sure that is true. Thank you so much.

Q143 **Baroness Barker:** The question of how to navigate the care system is not new. I remember, 15 or 20 years ago, Age Concern was doing work

on care navigation in what was then the epicentre of all things to do with health and social care, Torbay. It seems rather strange that, in a time when information technology has changed out of all recognition, we still do not get even general, let alone personalised, information to people to enable them to find what they need.

Do you know of any system that works well in which there is a centralised point of contact with somebody with the power to make things happen? Just simply, do you know of any information systems that work?

Tricia Nicoll: I love the idea that there would be a central system with someone with the power to make it happen. How amazing would that be? The answer is no, I do not know of that.

Baroness Barker: May I perhaps give you an example? I have recently had occasion to talk to people about Parkinson's disease. They are quite clear that, when you have a diagnosis of Parkinson's, you have a specialist who makes the diagnosis and you have a GP. Neither of those two people knows what to do. The people who really know what to do are the Parkinson's nurses who know what happens and how everything works. For some very specific conditions, although there is not a centralised system, there is somebody sitting in a key position who can help people to navigate through. That is the kind of thing I am looking for, if you know at all.

Tricia Nicoll: Yes, completely, and you are right. You are describing specific medical conditions and impairments that have—a word I never use—a pathway. If you get diagnosed with Parkinson's or motor neurone disease (MND), they are medical conditions that require some medical support, and you want someone who is a central point. Even someone who lives with type 1 diabetes will have a diabetic nurse. You will have an MND nurse or a Parkinson's nurse, so you are right. That works. I can see that working.

For the majority of people who are drawing on social care support, it is not as neat as that. I am thinking about myself and my kids. It is not about someone who is an expert in my impairment or my condition. I want someone who is genuinely interested in listening to me tell them what it would take for me to get the life I want, to continue to live my life, to continue to go to work or for my kids to get what they need out of their lives and have those aspirations.

I would still say that the best people to help you navigate the system are those with lived experience, and not just those in informal roles, but those in paid roles in formal disabled people's user-led organisations, because they are beyond impairment-specific. That is the point.

It is about the system and the network of people. I still use words such as "battle" and "fight", as Katy, Helen and Norman were talking about. The people I go to for help are those who know the system and have lived experience of it. That is who will fight with me and for me, and it has to be hyperlocal. You cannot just think about a whole local authority area such as Kent, Durham or Northumberland, which are huge tertiary

organisations. You have to think hyperlocal about people who know your locality, know you and what the set-up is, and understand how things work.

My thinking and my experience is that that is best done by people who have and can draw on that lived experience. I am talking about paid roles. I am not just talking about informally; I do lots of informal stuff as well, but there need to be those paid roles.

Q144 **Lord Laming:** Andy, this follows on very nicely from that discussion we have just been having. We would like your thoughts about peer-led organisations and activities. Would it be possible, desirable or worthwhile to arrange for people who need assistance of one kind or another to always be directed to a local peer-led organisation? Is this a sensible and achievable suggestion?

Andy McCabe: The short answer is yes. The longer answer is that, as we have heard, peer-led organisations and disabled people's organisations can provide a blend of professional advice on rights and obligations from capital P professionals with lived experience that gives you a depth of knowledge and navigation that you cannot get from working purely with capital P professionals. It also provides camaraderie and understanding of where other people have been through similar things and managed to get through it in lots of different creative ways.

One of the fundamental and positive things about disabled people's organisations and peer-led organisations is that they can support individuals with challenging the local authority and its decisions, which, perhaps, people such as social workers are not in the best place to do. At least, it does not feel like it because there is that lack of independence. I said this in the previous discussion about having an independent third-party provider being able to provide that kind of advice if you have disputes or disagreements with the local authority. Peer-led organisations are situated in one of the best places for that.

Having said that, as Tricia said, one of the problems I found from personal experience of working with, now, two or three disabled people's organisations or peer-led organisations is that the funding is often given by the local authority. Once the organisation starts rocking the boat slightly, the funding quickly starts getting pulled away, or at least there is the threat of that. That means that these organisations cannot be truly independent or, if they are, like the ones that I was with, they just lose their funding.

That is hugely unfortunate and very counterproductive because, in the end, everyone should want the best outcome that enables the most people in the best way. If that involves challenging the local authority from time to time, here, as a group, we would accept that as necessary to create positive change, but also to hold people to account and make sure that best practice is being delivered.

There has to be some sort of protection for these organisations, in terms of them being set up with funding and having continued funding to increase training throughout them to support the quality of information given.

On one thing that has not been mentioned, I personally got support from these organisations, which drew me into the organisations because I then wanted to be part of providing that support. There is this mutual circle in which everyone makes a community; everyone learns a bit. I give a bit; I learn a bit. It feels really great. Then, if you are able to add paid roles in there, everyone is getting respected—in the organisation, certainly.

The next step is to make sure that the local authority treats the organisation and the people in it with the same respect with which it would treat the people working for it directly, so there is not that hierarchy: "We are the social workers; we are the local authority and we make the funding decisions; and the peer-led organisations are second best to that." There needs to be some sort of collaborative effort where the individual, the peer-led organisation, the local authority and the social worker in there are all working from a place of trying to create the best outcome.

It also provides a great opportunity for social workers to get involved in a more community-based approach, and to work in a mediation or middle route, where the ultimate goal is the person with whom they are working.

Lord Laming: Am I right that your experience has led you to believe that peer-led organisations are very important in providing information, support and, where necessary, advocacy?

Andy McCabe: Absolutely, yes, and, even more than that, providing opportunities for people to feel part of a community and then, for want of a better phrase, give back. It creates mutuality. One of the biggest challenges is that, once you start rocking the boat, the local authority funding starts disappearing.

Lord Laming: That was my next question. How is it possible to have an effective peer-led organisation doing the kind of tasks that we have just described but also ensure that its funding is secure? Do you have any thoughts about how that funding arrangement might be made?

Andy McCabe: The best way to do it is probably to have funding for organisations that are evidently person-led—and disabled person-led, in that situation for disabled people—and then to ask the people who use their services whether they are bringing benefits, not necessarily what the local authority view of that situation is. The local authority's view, in terms of funding them, might be coloured by the challenge that they provide. The people who actually use those services—disabled people, individuals and families—may be better placed to verify them, say what is good and bad, and give feedback. The feedback should be from the individuals rather than the local authority itself.

Lord Laming: Do you agree with comments made earlier that it is essential that such organisations are local and not countywide?

Andy McCabe: Absolutely, yes. An even bigger problem I have seen personally is nationwide organisations, with large amounts of funding and the ability to influence local authorities by providing services at cheaper rates, swooping in and taking up lots of services, not providing good value for money, and not even providing much in relation and in comparison to a very localised service. Local people supporting each other mutually, with the local knowledge that cannot be gained by growing bigger and bigger, is the place to start for that particular way of working. Localised and more localised is better in that situation.

Lord Laming: That is very helpful. I am very grateful to you.

Tricia Nicoll: I completely agree with everything Andy is saying. I think he said this, but I want to make sure it is really clear. What that organisation looks like locally needs to be decided by local disabled people, not by the local authority. We tended to find, with disabled people's user-led organisations, that the local authority would say, "Here's what we think you need to do as an organisation and this is what we want to commission", rather than talking to local people, letting them say, "This is what we need" and then agreeing outcomes mutually. There is a subtle but really important difference there. Handing over the idea of what that should look like to local people and letting them grow it rather than it being set up by the local authority is a fundamentally different way of looking at things.

Lord Laming: They must be independent.

Tricia Nicoll: They should be 100% independent from the word "go", as in genuine co-production: "We've got this idea. You've told us we need this thing. As a local authority, we don't know what that needs to look like, but you guys do, so we'll trust you to do that." That is what is needed here.

Q145 **The Lord Bishop of Carlisle:** Andy, this is another question for you. We are conscious that not everybody has relatives or even friends in a position to provide unpaid care. Even if they have, they may not wish to draw on that care. We have heard a lot about the PA (Personal Assistant) system being a very good means of enabling independent living. Have you found that that is the case, either for you or for others, and, if so, what are the main problems in accessing that? How could those problems be overcome?

Andy McCabe: It is a big question. It is a preferable model in most cases, but control and choice should be at the heart of it. On the flipside, if people do not necessarily want PAs in that way because the admin is too onerous or they do not want to be an employer, there has to be something else there for them. A spectrum of support is needed, where at one end someone is a complete employer with a PA, and at the other

there is a lot of support and direction from the local authority, with individuals still at the heart.

In terms of barriers to an effective PA system, the first is the lack of knowledge about direct payments and PAs. That comes from the local authority itself but also from individuals who could benefit from them. This could be improved simply by having good-quality information and advice and guidance that are up to date. In the previous chat, Helen mentioned that being up to date and valid is important. In my own experience, many of the documents I have been given by the local authority have been wrong, have been five years out of date or something like that. It is very hard to work from a place of confidence or knowledge when you are being given things that are just incorrect.

I mentioned this previously, but it is worth touching on. A more overarching barrier is people who are just fearful of contact with the local authority or social workers in general. The face of the local authority, social workers in particular, in these groups where it is about supporting people with care, needs to be made more friendly and collaborative rather than conflict-based. The ultimate goal should be that we build lives for people that they want and are happy to live. That is quite a good basic goal. I hope there is an ability to ensure that people feel comfortable and confident that the local authority is trying to act in a way that is beneficial for the person involved, so that they are not put off.

One of the big barriers currently, which has been growing as a problem with PAs in general, is trying to recruit staff. That has become a big problem. One way of trying to overcome that barrier is to publicise the role of the personal assistant so that people are aware of what it is and that it could be quite a good job for some people. There are lots of people, certainly some who have worked for me, who have never even considered or known that it was an opportunity. Actually, it is quite flexible and a bit different from the usual nine-to-five job, which makes it attractive.

To make it more appealing, we need to think again about increasing funding because the pay is not the best. I have to pay minimum wage because of the hours I have. It is a job with a high level of responsibility and skill, and that should be respected. My attention was drawn to this a few years ago at an event with a local authority chief executive, who was proudly saying that all the council employees, at the time, were paid well above the living wage, which was a few pounds over the minimum wage. Yet personal assistants do not feature in that at all because they are not directly employed by the council. That creates a discrepancy in how they view their own direct staff, which is telling as to how they view personal assistants.

One large part of your question is about people who do not want to rely on friends and relatives for unpaid care. From people I know, the reality of this is that there is an expectation and pressure from the local authority that, if people live with family members, they will provide a large amount of the care. It is an uphill battle to get care and support

that mean the person is independent, with or without the family. Katy mentioned the knock-on effect on carers' health as well there.

This needs to be changed as a culture. The simple way to rectify that is to ensure that families and individuals who require support are given a free choice in how it is provided. The options given are clear, and that includes the option of saying, "Yes, I live with my parent, parents or partner but I don't want them to have to provide X amount of care; I would like my care package to reflect this", without a battle. As with many people I know who rely on unpaid care, often, once you provide some unpaid care, for lack of a better term, the local authority will try to push that until it is the maximum that is provided, which is not a fair situation at all.

On top of this is the barrier of understanding to the fact that family members can be paid through a direct payment budget. In the current climate of difficulty of recruitment, that is sometimes the only option because family members are familiar with lots of elements of the care package. Being able to pay them would be of potential benefit to some people. It should be reflected that family members in the same household could be paid as well if that is a free choice made by the individual. Fundamentally, answering your question about unpaid care, it is about reflecting and recognising that there is a lot of pressure on people, whether or not it is openly admitted by the local authority, to provide the maximum care they can, until it is at breaking point basically. That is the point at which they will stop. That is how it feels and how I have seen it play out with people I know.

The Lord Bishop of Carlisle: That is a really helpful and comprehensive answer. Thank you very much indeed. I have one extra thing on top of what you said, which is to do with training. You said it is often hard to recruit because people do not even know that the option is there. We have certainly heard that from others, but there seems to be a lack of training of people to do the job in the first place. Is that your experience, Andy?

Andy McCabe: I am, in my situation, able to train people up to the way that I like to live and the things that I do, which is also a great part of the PA system, because everyone does things differently. What a care agency provides is very different, necessarily, from what individuals want. More training and availability to train people formally would be great because people would also feel like they are progressing in a role and all those things that can be nice. Fundamentally, in terms of people knowing about it as a role, there could be much better visibility, supported by the Government: "Here's what PAs do." They do it with all sorts of other professions and there are plenty of PAs in the UK.

Q146 **Baroness Goudie:** I have found all your answers very interesting and very upsetting about the way people are dealt with, as I have said before. Andy, one of the things I feel very strongly about is people being able to have independent living. What are the key challenges you have faced in accessing housing, and what are the most relevant changes that could

happen to remedy the accessible housing crisis for people in care? Besides building more houses, what else could be done with the existing housing stock, whether it is private, public or whatever?

Andy McCabe: I am glad you used the word "crisis" in there because it is a crisis. I am currently in the midst of moving house. I have seen this crisis up close and personal from a rental perspective and a purchase perspective. I would like to make really clear, though, that accessible housing is not just about living in a house that is accessible. Looking at the statistics, I found that roughly 5% or 6% of homes in the UK can be visited by a wheelchair user. That is a bigger issue because it impacts social life as well. I found, when I was visiting people at school, college and after, that I could not get into the majority of their houses. It is a much wider-reaching issue than just where you live. That said, I know this is not the question, but there needs to be a minimum number of accessible properties being built; that needs to be very strictly done.

As for changing the current housing stock, the Disabled Facilities Grant needs to be expedited, because the average wait time is five or six months to get somewhere adapted once it has been accepted. I know they have a maximum time limit of six months before they approve it or do not. That is a really long time to live without a toilet. In my situation, I can start that process properly only once I have actually moved. There is no prior speeding up of that process, so clear access to the Disabled Facilities Grant and support there would be great. Expediting that process to be very quick would at least improve changing housing stock where there is a clear need for adaptations.

For instance, should you want to build on to your own house to make it accessible, if you are familiar with permitted development of houses, there is a very expedited process of building on small extensions et cetera without needing full planning permission. That could be reflected for accessible adaptions, so that the planning process is very quick, almost a tick-box exercise: where it is clear that someone needs X, Y and Z in their house, it is accepted and ticked by the local authority, rather than dragging that process out massively for planning permission.

There is also potential for disabled people to have preferable planning treatment in building an accessible house from scratch. That could be supported by government loans and, if the disabled person cannot afford to buy it, that could be considered housing stock at some point, or the disabled person could be supported to buy that. Recognising that the planning laws are very restrictive, which further compounds the lack of housing, there are many things that could be done there to improve it.

Another thing I found difficult in trying to move was being told blankly that they would not rent to people on benefits, basically. I know there are things already in motion there to improve protections, but that needs to be protected and those rights need to be pushed forward, because being told that is not helpful. It means that lots of people in my position just cannot rent a house and, once they do, it is very unlikely to be adapted, so there is a bit of a Catch-22 there in terms of private rentals.

The other thing to remember, thinking about this housing crisis and lack of rental properties, is that it means people are living in potentially unsafe situations for extended periods. Those unsafe situations can arise from the physical environment that they are living in or a familial environment that they need to move away from. It is not just a case of people being uncomfortable or finding life difficult. It could be a very dangerous or risky situation, so the lack of accessible housing is actually keeping people in unsafe situations. That needs to be given a bigger priority than it has been. There are so many elements of housing, from planning and building new houses to rental, that really need to be looked at with urgency and as the emergency situation that it truly is for many people.

Baroness Goudie: Thank you very much for being so open and for reminding us, as we needed to be, about the benefits issue, the length of time to get planning and the secondary benefit. This has to be sped up in one way or another. Thank you very much.

The Chair: Thank you, Andy. That was a very comprehensive answer and very helpful.

Q147 **Lord Bradley:** Hello again, Tricia. When you first provided evidence to the committee, you suggested that adult social care is not only invisible but misunderstood by the general public. You have reinforced that view very well today. The committee has also heard that it is critical to raise the profile of social care, both from the top down and from the bottom up. Would you see any value in the proposition to create, for example, an Older People's Commissioner, a Disability Commissioner or, as Katy suggested, a Carers' Champion nationally?

From the bottom up, would you see a new opportunity to ensure that the user-led living experience organisations are embedded in local place-based commissioning under the new integrated care systems of the Health and Care Bill? If no to both of those, how would you attempt to raise that understanding with the general public?

Tricia Nicoll: Local disabled people's user-led organisations should 100% be embedded as part of place-based commissioning. For me, it always has to be about the voice of lived experience. In terms of a national figure, I am a bit cynical, I am afraid. It would have to be someone with lived experience. We had the *Valuing People* White Paper 21 years ago, and I was part of the *Valuing People* support team. We had the amazing Rob Greig, who was the voice of learning disability and did some amazing stuff, but it was transient. He managed to do some absolutely amazing stuff by being the voice of people with learning disabilities and families.

For me, it is much more about challenging public attitudes and the things we are trying to do through Social Care Future in terms of the narrative, the language and the way we speak and think about everything to do with social care, so that it becomes ordinary: "Yeah, I need some help to do that and therefore that is part of my entitlement." Before personal budgets were embedded in the Care Act, we used to talk a lot about the

entitlement to that funding. There has to be something about that language of entitlement, rather than all the stuff that Andy was saying there about family members feeling pressurised into support.

If I need support to do stuff, I want that transactional relationship with somebody else who is paid. I do not want somebody who loves me to be doing that. My mum lived with me for the last 13 years of her life. For the last year and a half, when she needed some help with personal care, she categorically did not want me doing that. I wanted to respect her dignity, so we made sure that she got paid support to do that, which enabled me to be a daughter. It is those sorts of stories and narratives. It will grow locally.

I would be interested in what Andy felt about this but, potentially, the strength is in that change locally. Nationally, it is much harder, but it has to come through things such as our media. I still regularly shout at the radio and the newspapers for the language that they use around disability and impairment—"the vulnerable" and "tragic figures". We still have that narrative around people through our media. That has to change. Again, years ago, in our team, we talked about the most powerful thing being, potentially, for someone with an overt learning disability to be on "EastEnders". People being present in ordinary roles can make a difference.

I am not convinced about the idea of tsars, as we called them back in the day, 20 or 30 years ago. We always used to say, "Remember what happened to the tsar", so I am not convinced about that role, if I am honest. My only proviso would be that, if it was someone with lived experience in a very public ordinary position, I could see that being useful. Embedding disabled people's user-led organisations in local commissioning is definitely really important.

Lord Bradley: Those two elements are not necessarily mutually exclusive.

Tricia Nicoll: No, they are not.

Lord Bradley: If there was a champion for carers in the way that you describe, related to what was happening on the ground locally, that could raise the national profile of what is happening in local communities and give confidence to people locally that there is a route into that system.

Tricia Nicoll: It could. You are right that they are not mutually exclusive. I can see someone with lived experience in a role directly about people with lived experience. The role around families and support from loved ones is much harder. I do not see eye to eye with your previous three witnesses; that is the truth of it. That is not how I see things and I know lots of families who feel the same way as I do. Equally, I know lots of families who feel the same way as Helen, Katy and Norman, so it is a more divided situation.

I loved what they were all talking about in terms of how unpaid support is valued, and I feel exactly the same way about predominantly mothers staying at home to look after children. I feel that is no different. It is what we think about as the core economy. The core economy is run mainly by women in unpaid caring roles, caring about people mainly by looking after kids. If we had a different approach to childcare, as we see in Scandinavian countries, with an expectation that women want to go back to work and that there is a beautiful and wonderful system of childcare, we might have the same thinking around people who need support when their loved ones need support. That is a bigger thing for me.

Lord Bradley: Thank you very much. That is very helpful.

The Chair: We have come to our last question now, rather sadly. I shall ask Lady Shephard to wrap up with her question to both of you.

Q148 **Baroness Shephard of Northwold:** I would love to ask this question, because it is a multiple question. It is to all our excellent witnesses today. What has been so interesting is that there really is a divide in their passionate opinions about what constitutes caring, the role of families or the separation of families from the caring function. It has been fascinating and it has been wonderful to see people again, which is often something you do not get the chance to do on a Select Committee.

Anyway, we put to you a range of questions. You have given us a range of views. Are there any other key issues that any of you would like us to acknowledge when it comes to improving the lives of individuals with care needs? Have we left anything out? That is the thing—probably a lot. Who would like to start the answers there?

Helen Spalding: There is an issue that has come up very recently. My daughter is now 23. She has severe learning disabilities and now has complex mental health problems. She goes to day services. She is very lucky: she has a package that means she can access day services five days a week, which, I think, is not out of the realms of reality, but it is deemed a really great package.

The problem we have is that day services are very limited and not flexible at all. Where my daughter now has been assessed as needing one-to-one support, we have to go through a process to get that support for her. We do not know how long that will take. I understand, obviously, that they have to recruit staff. My daughter goes to two different day services, so it will take a while. In the meantime, if they have difficulties, I will get called in, and I will take my daughter and look after her, because then they do not have the staff to do that until they can get the one-to-one support in place.

The thing is that the day services are not flexible; they are not allowed to be flexible. Now, I do not run a day service and I do not know the ways in which they are unable to be flexible, but I was saying that it might be best, for example, for my daughter to go each day for half a day. Then, if she had one-to-one support, she could just go off from the day service

and do another activity in the community—maybe bowling, swimming, going for a walk, going for a coffee or going to the cinema with her one-to-one support. Apparently, that cannot happen. I was told very definitely by social care and by the day services that it cannot happen.

It just seems bizarre to me because, again, we are trying to fit everybody with some sort of special educational need and disability, or whatever you want to call them, into one box. If they do not fit, that is a problem. It goes back to what Tricia was saying about having to change our attitudes. We need to change our attitudes towards the services. It is perhaps not so much about budgets because the money is clearly there. We just need to think outside these boxes. The services that are there need to be encouraged to look at being a bit more creative in what they can provide.

I live in Salisbury and there is a problem about the choice. There are only four day services, and they all look very much the same anyway. There is no range of activities.

The Chair: We have to stop you. I am ever so sorry, Helen.

Helen Spalding: That is fine. I will put it in an email.

The Chair: That would be great because we are slightly pushed for time.

Tricia Nicoll: What you have just described, Helen, is a beautiful example of the Care Act not working. Everything you have described is utterly possible. Your daughter should have a personal budget. How you choose to spend that personal budget is up to you and your daughter together. It is absolute rubbish that the day centre cannot do what you have described. Everything you have described is just not true, but you have been told it is the truth, so it is a beautiful example. We are in very similar situations. My daughter has just had lunch in Pizza Hut with her two PAs. That is the difference, so that is a really good example of the Care Act not working.

As a follow-on from Andy's question about accessible housing, for young disabled people, particularly young learning disabled and autistic people, we do not assume that what they want is a house. We try to package up their support and where they live together, and we assume that people want to live in congregation. That is true of older people as well.

One thing for me around the housing question that has to keep going is that, generally, as adult human beings, we do not choose to live in congregation. We choose to live with someone we love or with a partner, we choose to make a family or we choose to live on our own. We choose to organise how our support happens. I am using the word "support" in its broadest sense, such as who might clean our house, help us with the garden or whatever. We choose to decide that we want to do that.

For a lot of young disabled people and for older people, generally, we want to put all that together, the idea being that where you get support and where you live are the same place. I am having to fight really hard

for my kids, who are in their 20s—it is time for them to move out and get their own place—not to be pushed into residential care. They want a house that is accessible to them. They have a great support team already, who want to go with them, so that will be the big thing for me.

Andy McCabe: I have two points that we have not touched on today. I will keep them brief. Really, this whole discussion is about maximising independence in an effective way that works for the person we are working with. A huge barrier for me and many people is the fact that there is a contribution to care that costs an excessive amount of money, which is not sustainable for a lot of disabled people and is pushing them into poverty. That is as bluntly as I can put it. It is causing a lot of mental anguish and mental health problems. Even if it was not, it would still be morally wrong.

It needs to be highlighted massively that people in my situation are having to pay anywhere from £80 to £120 a week from their means-tested benefits. It cannot be right that that is happening, so that should absolutely be picked up, looked at and—as has been done in some local authorities, so it can be done—just taken away completely.

Following on from Tricia, one issue about benefits and living with people is regularly brought up to me. I hasten to say that the word "vulnerable" here is not used in the way that Tricia dislikes, as a state of being for disabled people; it is about how we make people vulnerable as adults. If someone in receipt of means-tested benefits moves in with a partner, they can lose all their means-tested benefits, and then their partner is expected by the local authority to provide some unpaid care.

This limits the lives of many disabled people who rely on means-tested benefits, and it means that they become majorly reliant on their partner for finances as well as, potentially, care. That not only limits their independence but creates circumstances that, potentially, increase vulnerability to abuse and such things. It is incredibly important and this is brought up with me quite a lot by disabled people. It is part of this conversation about care and trying to let people live the lives they want to live. Once you start taking finances away from people, it is very quick to get rid of their independence. They would be my add-ons.

The Chair: They were certainly worth hearing. Thank you, Lady Shephard, for that. Thank you to both Andy and Tricia for taking us through that session. What has been interesting is to hear you speaking to each other, supporting each other, commenting with each other, learning from each other and advising each other. That, in a way, is part of the privilege of our almost eavesdropping on those conversations. You shared your insights with us as you did before. You have helped us clarify some of the things we definitely have to say and some of the things that we should think carefully about, because they have complex implications and will impact differently on different people.

It has made our challenge both clearer and more challenging, which is exactly what we would want. We would not expect anything less from

you. Again, thank you very much for making your time, knowledge and experience available to us so frankly and so very insightfully. With that, I will say that we will be in touch and I hope that, when we produce our report, you will feel you have had a part in it, and that you can identify with and be proud of it. Let us hope so. Thank you very much indeed, everybody.