HOUSE OF LORDS

Adult Social Care Committee

Corrected oral evidence: Adult social care

Monday 25 April 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 Goudie; Lord Laming; Lord Polak; Baroness Shephard of Northwold; Baroness Warwick of Undercliffe.

Evidence Session No. 6 Virtual Hearing Questions 55 - 59

Witnesses

I: Nadia Taylor, Chair of the Board of Trustees, Carers Network; Valentina Zigante, Research Officer, Care Policy and Evaluation Centre, London School of Economics.

Examination of witnesses

Nadia Taylor and Valentina Zigante.

Q55 **The Chair:** Good afternoon, everyone, and welcome to this session of the Select Committee on Adult Social Care. We have one unavoidable absence with an apology from Baroness Jolly, but otherwise we are all here. We are taking evidence this afternoon on unpaid carers and poverty.

We have two sessions in the next couple of hours. For the first session on unpaid carers and poverty, we have the privilege of hearing from Nadia Taylor, who is the chair of the board of trustees with Carers Network, and Dr Valentina Zigante, the research fellow at the Care Policy and Evaluation Centre at the LSE.

The second part of the session is on unpaid carers and work, particularly for people who are of employment age. We will be hearing from Madeleine Starr, the director of business development and innovation at Carers UK, and Sue Yeandle, professor of sociology and the director of CIRCLE, the Centre for International Research on Care, Labour and Equalities, at the University of Sheffield.

Those are four very distinguished guests, and they are very welcome to the committee this afternoon. As you know, we are exploring in this short but very intensive inquiry the concept of invisibility in adult social care, and how it bears down on the people who provide care and puts the unpaid carers in focus, as well as those who receive and need the care that they give.

One of the issues that has come up many times already in the evidence we have collected is the link between unpaid care in this part of the caring community and poverty. We want to explore that in some detail with you this afternoon. It obviously affects different people of different ages in different ways. It obviously brings together a whole range of interrelated benefits, provisions and services. It exposes both the ambitions of the adult social care system and the failings of the benefits system in relation to that system.

At a time when there is such grave concern about cost of living increases, this issue becomes even more acute. We are very keen to hear from your experience and your knowledge of unpaid carers and the people they care for, whether they are not in work or in work, how you think the system is working; what you think the implications are; where it could or should be changed for the better; or indeed anything that you want to tell us.

As you know, this session is being broadcast, so there is a wide audience with a wide interest in the topic. We will provide you with a transcript.

I will start with a very basic question for Nadia and Valentina. It is one that we have to ask because we want to hear what you have to say on the record. As I said, we are very interested in understanding the scale and the depth of the financial hardships faced by unpaid carers who are unable to remain in employment and who, as a result, have to rely on state-funded benefits. To what extent are the existing benefits sufficient,

in your view, to support unpaid carers who do not have an income from paid work? What are the consequences for this enormous group of people?

Nadia Taylor: Thank you very much, Baroness Andrews. As you know, the only state-funded benefit specifically available to carers, subject to eligibility criteria, is Carer's Allowance, currently at the rate of £69.70 a week. This amounts to £3,624.40 a year. I understand that there may be some additional payments available to carers in Scotland and Wales, but not to carers in England. It is also possible that some carers, depending on their personal and household circumstances, may be eligible for other benefits. However, many carers providing around-the-clock care for loved ones, for one reason or another, are only eligible for Carer's Allowance, as they narrowly miss the eligibility criteria for other benefits due to the inflexible, and in my opinion rather unfairly structured, benefits system.

I am one such carer. I doubt that anyone in the House or indeed in the country would consider a personal annual income of £3,624.40 sufficient. It is outrageously low. Unpaid carers make extraordinary sacrifices while having to cope with immense personal challenges, physically, emotionally and financially. We have put our lives on hold and we need meaningful financial recognition.

I am 46, a university graduate with a background in international relations and experience in licensing law. For 22 years, the last 14 of which have been full-time, I have been caring for my parents who suffer from a number of chronic medical conditions and have complex medical needs requiring 24-hour care. I have a husband with a serious chronic health condition and two teenage children, also with health issues.

I can honestly say that I have been exhausted for 22 years. I have not slept for 22 years. I have not had a respite for 22 years. I have long since used up my savings. I have more often than not been unable to fill my prescriptions because I simply cannot afford them. I have a heart condition. I suffer from arthritis, asthma and scoliosis. I struggled for eight years juggling caring for my family while maintaining a full-time job until I was forced to give up my work and become a full-time carer.

My loved ones are very dear to me. Caring for them is immensely rewarding, as is the knowledge that they are safe in my care. However, as you can imagine, I have had to put my personal ambitions and professional aspirations on hold, and frankly, my own health and well-being on the back-burner, because, for unpaid carers with demanding caring roles, caring is a long-term and life-changing commitment.

Unpaid carers are not protected by statute and are therefore excluded from any provision of statutory sick pay, holiday entitlement, pension arrangements—other than the national insurance contributions—or any help with healthcare costs. Many unpaid carers fall outside the exemption from paying for prescriptions based on age and benefit entitlement; they are free for everyone in Scotland, Wales and Northern Ireland but not in England. They struggle to afford their prescriptions, much less dental and

eye care or transport costs to and from appointments for themselves and the persons they care for.

Therefore, what would really help and make a difference would be for the minimum living wage to be extended to unpaid carers so that we were given parity with the rights and provisions for other benefit recipients who, unlike the recipients of Carer's Allowance, are entitled, among other things, to free prescriptions, eye and dental care and subsidised travelcards.

The Chair: Thank you, Nadia. You mentioned the minimum living wage. Is that something that Carers Network has been campaigning for? Is that your prime concern?

Nadia Taylor: The Carers Trust has. Carers Network is not a campaigning organisation. A couple of years ago, we changed the Articles of Association, opening up the way for us to campaign a little more. What is really needed is a partnership between all the agents in the network: the Carers Trust, the Carers Network and other charities, as well as the local authority. We need a change in national policy. We need formal recognition of unpaid carers, which is not the case now, despite the existence of the Care Act 2014.

Of course, it somewhat defines us, but it is merely a gateway to having a carer's assessment. It is not solving the problems that we experience on a daily basis at all. You mentioned the rising cost of living. We are absolutely abandoned by society. I look forward to the remarks that will come later and to hearing what colleagues and supporters feel. From where I am standing, it is a very lonely place. I look forward to sharing with you the challenges and obstacles that we have encountered, both as an organisation at the Carers Network and as a carer myself, and how society views me since I have stopped working.

The Chair: Nadia, you silence us when you tell us what you have done and what you have both gained and lost. Caring for five people in your family and being such an active advocate is a remarkable achievement. I will leave my colleagues to follow up some of the really important issues that you raised. Valentina, what is your perspective on that very basic question?

Valentina Zigante: It is very hard to follow Nadia. I am listening to this today on a research level. I can only offer evidence on the broader structural implications of what Nadia was describing so eloquently that it has made us all quite emotional.

From census data findings, there are 1 million carers who provide more than 50 hours a week. There is no possibility of doing any work when you are providing that amount of care. There are estimates of the value to the economy of that care. They are difficult to judge, but they are huge. The value to the economy that carers such as Nadia are offering is massive.

I can only echo that the carer's allowance is very low comparatively. We have only looked at European countries and it is definitely on the low side for direct benefits. Nadia did not touch on this, so I am really interested to hear if she has any experience of what benefits the people she cares for are receiving. In a lot of European countries, that would be a way of offering more money to unpaid carers. It would be indirect benefits—according to the choice of terminology. Where there is a formal employment contract, you become recognised through the care package that the user is receiving. I see that as quite a promising way of approaching it. In England, that would be the direct payment. Those exclude co-residential carers on principle. I think it is better since the pandemic. There is a bit more leeway, but unless it is necessary from the point of view of the local authority, direct payments are not channelled towards people who are providing that kind of 50 hours-plus a week care. That is a really important point.

I want to emphasise all the economic evidence in favour of the importance of keeping carers healthy and in a good mental state and supporting their physical and mental well-being. There is lots of research on how financial strain very much feeds into the overall perception of strain in the caring relationship, the caring situation.

When it comes to prevention, we know very well that carer breakdown is what causes people to need to go into residential care. It is massively costly in economic value to society. Unpaid carers offer such an important service. We should see supporting carers as a preventive measure ensuring that the users can stay in what is usually a very positive caring situation. As Nadia was saying, many people prefer to have that family care-giving situation rather than being exclusively cared for by formal care services.

In supporting that to continue in a good way, I can only echo what Nadia said about thinking of ways of recognising that relationship, and formalising and ensuring that all the rights that are associated with formal work can be present in that situation too.

The Chair: Thank you very much. I have one quick question, Valentina. How secure are the statistics on the economic benefits?

Valentina Zigante: They make me slightly uncomfortable, which is why I did not quote any particular one. They measure different things so it is important to be clear about the underlying assumptions when interpreting those numbers. We have not carried out this kind of work at CPEC but I would be very keen to do it. I have seen one that is about £20,000 a year on average. Obviously, that ranges from people who provide a very small number of hours to people who do very intense unpaid care.

The Chair: Yes, I think it should be done. There are different statistics coming at us from different angles, but clearly no one is disputing the gap between what carers get and what they contribute. It would be good to have as sound a picture as possible.

Q56 **Lord Laming:** Nadia, thank you so much for sharing your personal circumstances with us. It was most helpful and most revealing. Could you help us a little more? The role of carers is very ill defined. There are said to be millions of them. I wonder whether a local authority has evaluated or assessed the caring needs of your immediate relatives, and whether there has been agreement as to what caring is needed.

Nadia Taylor: Yes and no. There have been many interventions over the last 22 years, as you can imagine. It was, unfortunately, the terrible experience of carers provided by the local authority and various agencies that led to my having to make the choice to leave work and care for my parents.

We have had carers who gave my parents the wrong medication. Agency carers tend to spend an hour in your home and a few hours elsewhere. En route, they collect the prescriptions. They arrive at your home and you happily leave, because they are going to be providing what you would consider relief or respite, but you return to find out that they left a lot earlier than they were supposed to. As I say, they will have given the wrong medication because they have collected medication for a number of cared-for people.

I should have explained that my mother is blind, among a whole host of medical conditions. She is obviously very dependent on the carer. My father is currently undergoing chemotherapy for a myeloproliferative disorder, so you can imagine that they are quite vulnerable. My mother has been brought home from hospital by hospital transport without me, because there is no provision for the 'informal carers', as we are known, to accompany the cared for on the way back from the hospital.

She has been delivered and literally parked on the street in the wheelchair with the key dangling off the handle of the wheelchair, because apparently— and this was not something I was told at the time when the key was collected from me—they were not insured to turn the key in the lock and enter the property. Imagine a blind lady who is already very vulnerable and rather unwell for many other reasons, finding herself on the street with everybody coming and going past her, not really knowing where she is or why she is there, while I run after her, catching two buses from Charing Cross Hospital, racing home to ensure that she is not left alone for too long after being dropped off.

Those were the sort of experiences that led me to think that something had to give. I have to say that it was not an easy choice to make. Emotionally, obviously, you jump to help, but financially it is incredibly hard because you lose your income overnight. Effectively, my husband, whose income fluctuates, is supporting four adults and two children. You can imagine that is really hard for the family.

What is available through the local authority is something that you always have to fight for. In theory, the assistance is out there. You can be assessed for this, that and the other, but in practice I do not think you

will ever encounter a carer who will say, "Oh, it was so easy and I got it all arranged".

Valentina mentioned direct payments earlier. She also pointed out that they are not really geared to support us. They are there if we want to grab what still feels like the odd hour of respite. But when you know who you are likely to be handing over the care of your parents to, it is very difficult to do. You end up doing it all by yourself.

Lord Laming: Are we right in thinking that it is impossible for you and the local authority to make a financial assessment of what would be needed to fund appropriate care for your relatives and for you to employ the staff to do that?

Nadia Taylor: People have different circumstances. In theory, there are mechanisms in place, and a support package can be worked out by the local authority, but there is a shortage of social workers. There is a large discrepancy between theoretical entitlements and what can practically be achieved. This is often due to inadequate budgets. Local authority budgets are for ever being reduced. Pre-elections everybody says, "Oh you know, we are improving packages a little bit and we are increasing the council tax to pay for it because we really want to help the adult social care department". Inevitably though, after elections, these promises are forgotten, and funding for adult social care continues to diminish, rather than increase.

To provide a broader analysis of how inadequate the benefits system is, carers come from all walks of life, as you can imagine and as I think somebody mentioned already. They have different personal circumstances and quite different needs of support. The existing benefits system is neither targeted nor personalised in any shape or form. It is therefore unable to understand, accommodate or respond to unpaid carers' needs. Indeed, I would go as far as to say that the State and the benefits system do not even acknowledge us.

As I said earlier, we are pushed to the fringes of society, completely ignored or often patronised by empty platitudes such as the statement "unsung heroes". Throughout the country we are often forced to depend on support and the limited services provided by charities such as Carers Network, for example, which is commissioned by the local authority to provide carer's assessments. The charity operates in three London boroughs, but it is dependent on ever-diminishing local authority funding and the charity's own fundraising efforts.

The interest of the House of Lords and its Adult Social Care Committee is heartening, but so far it has been impossible to encourage the powers that be, locally or nationally, to address the stark lack of support for unpaid carers by the State. Despite the enormous value of the economic contribution of unpaid carers, which is said to be around £132 billion a year, it seems that our plight has not produced the same amount of acknowledgement or sympathy as that for children or animal rights or, for example, the environment. No one wants to think of frailty, illness

and dying. Decision makers seem to forget that at some stage we will all need some level of care, and will be relying on good carers.

You talk about the local authority, which has expenditure on healthcare, but even the NHS has abandoned us because there is no official document to formally recognise us and the work that we do. We are not given any priority to be seen as patients. As I have already highlighted, many of us are unable to afford prescription costs. There is no understanding of the situations that we manage for and on behalf of the cared for, and no flexibility when arranging appointments.

Unpaid carers are often ignored in public discussions of health and social care. Frankly, even throughout the pandemic we were largely overlooked.

Lord Laming: I am sorry to press on, but we have a lot of ground to cover. In your personal circumstances, leaving aside healthcare needs and just thinking about personal caring, is the local authority contributing anything?

Nadia Taylor: Not at all.

Lord Laming: Tell us quickly, if you could, why that is the case. Why are your needs not recognised?

Nadia Taylor: Local authorities are quite pleased when a family member steps in, because then they divert funds towards whoever they perceive as more needy. The whole process of making that assessment is flawed.

My mother had an occupational therapy assessment that resulted in adaptations to the house. The bathroom was adapted for her needs, but that was probably over a decade ago. You try to request something from the local authority, but it is just not possible any more. The income thresholds of the system are so low. It requires an incredibly low amount of income, something like £16,000 to qualify for assistance. If the carer is not already receiving, I was going to say income support, but I think it is now universal credit—I have very little knowledge of the benefits system—they are immediately rejected.

Our boiler, cooker and fridge broke down at the same time. When you move house and you buy things new, they tend to last for the same amount of time. We suddenly thought, "My goodness, what do we do?" I sought assistance from the local authority. I sought assistance from the Carers Network. All the help that was available was for those who were claiming other benefits.

It is a different issue, but you may remember that there was the same debate when child benefit was removed by the Osborne Government. If you have two parents both earning just under £50,000—so lets say £90,000 altogether—they would still get to keep the child benefit, but if one parent was earning £50,000 that was the end of it. The way the whole system is structured, whether locally through the local authority or nationally, really does not help. It seems ill thought out.

Even with something basic like travel costs: the elderly, the disabled and young people have them subsidised. I do not know whether it is through the Mayor of London's office or through local authority budgets. So many groups in society have recourse to assistance with transport, but not us. How far can you stretch £69 of Carer's Allowance?

Lord Laming: I have one final and very quick question. Has anybody asked you what your needs are and how they could better help you?

Nadia Taylor: They have, yes. The local council always asks, but it does not like the answer. If I were bold enough to give you just an example, everywhere we turn there are obstacles. These are due, at the very least, to a lack of awareness and formal recognition of unpaid carers. If I may, I would like to provide a brief example illustrating this, and you will see that even among friends there is always resistance and doubt.

I have been volunteering with my local Healthwatch for some time. About two years ago, I pitched a proposal for a project dedicated to carers. You may have seen my draft proposal. There was strong resistance at first because neither the staff, nor the local committee members, believed it would be a worthwhile project to pitch to the Healthwatch leadership and the local authority for a number of reasons, ranging from lack of awareness and interest in the plight of unpaid carers, disbelief that the financial difficulties and the issues related to access to basic healthcare that I mentioned earlier were actually accurate and experienced by many carers, to the relevance of those issues to the local community and ultimately lack of confidence that we could achieve the kind of changes that I had been campaigning for, unsuccessfully, for years. Clearly, we need a change in national policy on unpaid carers.

It took many meetings and rather passionate arguments, as well as, frankly, quite a grilling by the committee and Your Voice in Health and Social Care, which is the local Healthwatch contract provider, on the validity of the data, despite it being widely available in the public domain through the Carers Trust, before the project was approved, with some modifications, which in my view, rather weakened the original intention, but it was grateful to see the project progress at all.

So, as the first stage of the project, a carer survey was published in February and has now closed. I worry that despite being approved, the project may still only really go ahead if enough data is collected to evidence the need. It is important to mention here that it is rather embarrassing admitting to financial and other difficulties and their impact on one's life. Many of us are isolated at home and locked in utter helplessness and despair, which in turn makes it very difficult to collect data because people are too embarrassed to share that information.

It is because of this that the interest of the House of Lords Adult Social Care Committee is so encouraging. I am immensely grateful. Thank you.

Lord Laming: Thank you very much. It is most helpful.

Q57 **Baroness Goudie:** Good afternoon, Nadia. I have listened carefully to what you have had to say. I understand how unpaid carers are treated and that they do not have the same respect and dignity that should be given to them.

From your experience of being an unpaid carer and of working with other unpaid carers, are there specific key areas in which carers require further financial support? Which are they? What should support in these areas look like? Perhaps you could put them from one to five so that we have the key areas and the committee can look at them later when we discuss this.

Nadia Taylor: Thank you very much. I will provide a much briefer response to this question. As I mentioned earlier, in my view, which I would venture to say is widely shared by fellow carers and our supporters who understand the many challenges we face, the existing financial support for unpaid carers in the form of Carer's Allowance is wholly inadequate.

We need fair and meaningful financial recognition, which can only come from an honest acknowledgement of our role and the work that we do. Ours is no different to any other role, be it part or full-time. The hidden workforce that is unpaid carers amounts to 6.5 million people in the UK and is expected to increase to around 10 million in the next eight years.

Carers Trust figures indicate that the estimated contribution of unpaid carers to the British economy, as Valentina mentioned earlier, is just under £20,000 per carer per year. Mathematics is not my forte, but receiving £69.70 a week in Carer's Allowance for a minimum of 35 hours of care is the equivalent of less than £2 an hour. More than 1.3 million carers provide 50 hours of care or more a week, and receive no more social security for it.

This cannot be right and fair in our great country, whose compassion and charitable assistance make a transformative difference in many parts of the world. We are not asking for charity. Unpaid carers deserve respect and to be recognised as part of the key workforce in this country. We need to be given an adequate, non-means-tested benefit in recognition of our work, or an appropriate wage, with the associated benefits, rights and protection. As the very minimum, we need the financial support to enable us to look after our own health and well-being by being provided with free prescriptions, dental and eye care as well as subsidised travel. We need to be treated with dignity and respect because it is quite simply the right thing to do, and about time too.

It is quite simple: formal recognition of our role and either an appropriate wage or an appropriate benefit that is not means-tested. People are free to do as many jobs as they like. Nobody is capping an income. As long as they pay their taxes, that is fine. Given that we do a job and we save the State an incredible amount of money, why are we abandoned? There is no protection for us. There is no insurance. There is no break. Formal carers—the care workers in care homes—have that protection.

Do you know how dreadfully heart-breaking it is when you are in a hospital with your loved one and you are completely ignored? People do not want to talk to you because you are seen as the nuisance who has nothing to contribute even when merely asking for understanding when you book an appointment. There is a distinct feeling that you are to be kept at arm's length. There is a complete and utter disconnect between the reality we live in and the way we are viewed by society, including the NHS, for example, or local authorities.

Recognise our role. Work out an appropriate wage and make sure that with that come the protection and the rights or, if it is a benefit, extend the vital access to basic healthcare just to help us to keep going and to keep us safe, so that we can then continue doing the roles that we do, assisting the State and reducing the number of social admissions. You name it, the list is long, but you know what I am saying.

Baroness Goudie: Thank you very much, Nadia. I really understand. I think the whole committee understands what you are saying.

The Chair: Thank you for saying that, Lady Goudie, and before we move on to Valentina Zigante I want to echo what you just said. We have heard extraordinarily powerful advocacy this afternoon from you, Nadia, from a personal and social point of view, so we are very grateful indeed.

Thank you for what you said about the importance of the committee. We fully intend to be as influential as possible. The sort of testimony that you have given us and the language you have used has been extraordinarily useful to us, so thank you very much indeed.

Q58 **Baroness Shephard of Northwold:** We have had a number of estimates while we have been taking evidence from people in the field, whether they are caring or people who are organising care, of the amount that the economy is saving through having such an enormous number of informal carers, some of whom would not even define themselves as carers. In particular, this is when a couple perhaps grow old together, and it simply becomes having to continue care for a husband, wife or partner, and then you are astonished to be called a carer. There are a number of difficult issues quite apart from definition, but I want to ask Valentina this.

We have had wildly differing estimates of what the state is saving. We were given a figure from 2017 that the state was saving £86.6 billion-worth of care because of the care provided by informal carers. I think we heard a different figure from Nadia today. I want to know if Valentina can throw a bit of light on this. Here is a truly horrific question for you, Valentina, because this is what we are struggling with and what Nadia has been so eloquently describing. How can you design realistic financial benefits for carers when there is such an enormous diversity of recognised absolute need and circumstances that of course, complicating the matter, change over time? It is a horrific question. It would be lovely if you could answer it. We are all struggling with it for the next six months.

Valentina Zigante: First, thank you for that really interesting question. It is quite a challenging thing to think about. Unfortunately, I have not done any of those estimates myself, so I feel hard-pressed to judge what the most appropriate one might be. There are obviously lots of assumptions that need to be made. From an economist's point of view——it could be about the value to the economy.

We could also think about the individual opportunity cost. What are they giving up? What is the value of the work they are giving up, the value of the leisure that they are giving up and all their time? These are all things that we value in the economy. It should be looked at more in those estimates.

In the absence of me being able to give you a clear answer on which estimate is the correct one, we can say that the value is massive. If we look across Europe and all the evidence that we have, we see that no cash benefit that is available is ever more than 75% of what a home-care package would be. Informal carers are always underpaid, whichever system we look at. One way of valuing that time would be to look at how much it would cost to provide formal care. People are providing round-the-clock care. The sums are staggering.

On the second—how we would think about designing a better system—a lot starts with the recognition that Nadia has been emphasising. It pains me a bit when she talks about it, because as someone who looks at the literature a lot I see that, in theoretical terms, in the English system, or the UK's various systems, people fare quite well. There are care assessments. There are mandated carer's assessments, and that is not something that we see in many countries. It is a clear recognition of carers' rights that there is the duty to provide a carer's assessment, but the problem is in the implementation of those rights. We have extremely cash-strapped local authorities, and even though there has been more and more money over the last couple of years, their budgets are very strained.

In thinking about how to design the system, there is something about who we need to be targeting, whether there is a means-tested benefit or a benefit that goes across the board, as Nadia was advocating. There is an issue about equity. If there is a non-means-tested benefit, there is always an element of people perhaps not needing the benefit and receiving it, whatever it is. To reach the people who really need the benefit, it is about making the system accessible, so that if there is a means test, it is easy to access and clear to understand. I have very brief experience of providing unpaid care, and I echo the exhaustion Nadia described. I have never been so exhausted in my life, mentally and physically. I have two young children and I know all about being tired, but this is something different.

In designing a system, you have to think about assumptions about the capacities of the people accessing the system. For alleviating poverty, a means-tested benefit would be the most overall economically effective way of doing that, but you need to address the questions that Baroness

Shephard mentioned. People do not see themselves as carers, and there may be stigma about accessing a means-tested benefit. Do people who need it want to do that?

My second question would be how much should be provided. The carer's benefit that is currently in place is very low, and internationally very low. The judgment would be about whether you are trying to remunerate the actual value of the work or replacing the lost income of not being able to work. That is a key point, and it is why it bothered me listening to Nadia. All these things are in place in theory, but when we are designing a system, particularly a system as complex as the adult social care system, because it is being administered by local authorities and there is the relationship with the healthcare system that Nadia alluded to as well, there is something about the implementation.

At the design stage, you already need to think about how it will be implemented, and then how it fits with the overall benefit system. I have been trying to look at research on this. I am not an expert on the benefit system overall either. I could tell you a lot about how things may play out for users of care or unpaid carers, but not about the benefit system as a whole. There is something about seeing how benefits actually fit together. A microsimulation model by the Department of Work and Pensions got me quite intrigued, for understanding how benefits cancel each other out. The rules on the carer's allowance are that it is related to pension credit, and if you are entitled to other benefits you will not receive it, et cetera. I think I have picked up most of my points. Perhaps I will leave it there.

The Chair: You can always write to us.

Valentina Zigante: I would be happy to.

The Chair: Tell us more. I am sorry to interrupt you, Lady Shephard. Apologies for that. In fact, we could go straight on to Baroness Eaton.

Baroness Eaton: Thank you. I apologise if I have missed much of what Valentina said in the previous question and answer, so forgive me if I repeat something that she has already—[*Inaudible.*]

The Chair: Have we lost Baroness Eaton? We will come back to her. Lord Polak, do you want to pick up some of that?

Q59 **Lord Polak:** Yes, I will. This has been a fascinating learning experience, and we can only sympathise. I guess all of us have some aspects of it, although not entirely in the way Nadia has it in spades, and we understand.

This committee is not able to wave a magic wand even if our Chair is trying to make every effort to do so. Valentina, if formalising unpaid care should be done, what can we recommend to move the dial just a little bit to help people like Nadia? What things can we do practically to start the conversation or help in the conversation?

Valentina Zigante: I used the term "formalisation" in a report, which is what you might be referring to—the formalisation of informal care. We are observing this across many countries. To me, it was quite interesting, because I observed it as something that is going on, and it has implications. It is interesting to think of that as a goal. I am not sure that formalisation is necessarily the best terminology—it is, rather, "recognition", or whatever we might call it—and it caused me to think a bit more about that. In the literature, we talk about co-workers and thinking about unpaid carers as co-workers in the system. I like that on a personal level. Some of that also depends on our cultural background and our expectations of the system, how we see ourselves.

If I reflect on my own biases, I am originally from Sweden where there is a much more formal, care-oriented system. To me, it makes sense that I was seen as a co-worker when I was an unpaid carer. If we were to move in that direction, a lot of the structures are already in place. The carer's assessments are already mandated. They should be carried out. There is also a lot of nuance in the language we use. I do not like the words "carer's assessment". It sounds as if you are being assessed for how good you are at caring, or I am not sure what. It should be about supporting carers.

The key is in improving indirect payments or the indirect benefits that you can access. There is, and has been in the past 15 or 20 years, so much talk about direct payments in the adult social care system. There is something about allowing that to be used for informal care or for unpaid care to really support that and to show that it matters. Obviously, there is the issue of the means test, because a lot of people are not receiving much care from local authorities at all. Potentially, that will improve over the next couple of years if the legislation goes through. We need to make sure that carers' assessments are carried out and direct payments can be used in a more formalised way. To me, that is key.

This is also something I would draw from the European evidence. The countries where I see best practice include Spain or the Netherlands. There are employment contracts in place. You are allowed to hire your wife, essentially, to be your carer. That then means that you are paid for what you do. The money is however never quite enough. We have to recognise the enormous costs of the adult social care system. Countries like the Netherlands spend a lot more than we do. There are issues to do with how much you are able to pay. It is very sensitive. It also links to strengthening the overall rights of unpaid carers, for pension contributions and social security in countries where that is relevant.

I hesitate to say this, but the only issue that comes up in the literature on this is that there are some countries that avoid cash benefits; they basically say, "You are paying people who are already caring, so why would you pay them? We're trying to save money". It is potentially true that you would be paying someone who already provides a service, and there is cost containment and all that, but it is not fair and it is not right. There is strong evidence that we need to support carers' physical and

mental health, avoiding strain as much as possible, at an earlier stage. There are clear savings in prevention, and the user deteriorating over time.

Lord Polak: If I can interrupt you, you have been very helpful, and you can be even more helpful to the committee. You touched on best practice in other places. It would be useful to pick up on that, even if to write to us. You mentioned Spain, and you talked about Sweden and other places. If there is something blindingly obvious that we are missing for some reason, whatever the reason is—I will not go into the politics of it—and there is something that would help people like Nadia along the line, it would be useful to know. That is the sort of thing that I am very keen on that we then promote. Thank you.

Valentina Zigante: I am happy to do that.

The Chair: Baroness Eaton, can you hear us now?

Baroness Eaton: I am sorry. You disappeared completely. I think I had better abandon speaking and just join in when I can by listening.

The Chair: That is very generous of you.

The Chair: That is the end of our first session. As I said to Nadia and Valentina, thank you so much for all you have told us this afternoon. It is absolutely invaluable. We will take the liberty of coming back to you and pursuing some of those issues, especially, Valentina, what you were saying about other countries, because that was the question that Lady Eaton was going to ask you. We would very much like to know whether there are other countries that approach this in different ways with greater success and greater fairness. Thank you very much indeed.