HOUSE OF COMMONS

Women and Equalities Committee

Oral evidence: Cost of living: disabled people and carers, HC 1037

Wednesday 1 February 2023

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Watch the meeting

Members present: Caroline Nokes (Chair); Dame Caroline Dinenage; Carolyn Harris; Kim Johnson; Rachel Maclean and Kate Osborne.

Questions 1 - 29

Witnesses

I: Louise Rubin, Head of Policy and Campaigns, Scope; Emily Holzhausen OBE, Director of Policy and Public Affairs, Carers UK and Salena Begley MBE, Partner Engagement Manager, Family Fund.

II: Jignesh Vaidya, Lived experience witness; Abigail Broomfield, Lived experience witness and Suzanne Buckner, Lived experience witness.

Written evidence from witnesses:

Examination of witnesses

Witnesses: Louise Rubin, Emily Holzhausen OBE and Salena Begley MBE.

Q1 **Chair:** Good afternoon, and welcome to this afternoon's meeting of the Women and Equalities Committee and our session on the cost of living for disabled people and their carers. Can I thank our witnesses, Salena Begley, Louise Rubin, and Emily Holzhausen for attending? Can I thank you all for coming this afternoon, and can I just check, are you content that Members of the Committee refer to you by your first names? I have nods from the two witnesses in the room, but obviously not from Emily who I can no longer see.

Can I just ask a very broad introductory question—I will start with Louise—about the impact that the cost of living is having on the disabled people that you work with and that you encounter in your networks? If you could keep it relatively brief, although I appreciate that you may well go into more detail during the course of wider questioning.

Louise Rubin: Broadly speaking, the impact has been devastating. We have seen a huge increase in disabled people calling us. We run a disability energy helpline in particular and we have seen a 500% increase in the number of referrals to that service. The crisis is affecting every aspect of disabled people's lives. We have probably all become quite familiar with the phrase "heating or eating" but it is much more than that from the calls we receive. We have people who are having to make awful decisions every day: whether they will have a shower this week, can they afford to heat the water, whether they will go to the medical appointment they should go to, but can they afford to get there? So, there is a really devastating impact for millions of disabled people.

Salena Begley: At Family Fund, we support families with disabled and seriously ill children and young people right across the UK and, just as Louise has said, the cost of living is causing extreme distress, both financial and in terms of health and wellbeing for the parent carers, for disabled children and for young people who are missing out on vital opportunities for their health, wellbeing and development, and for the siblings of disabled children and young people.

Thousands and thousands of families across the UK are struggling to recover from the impact of coronavirus, and our families were disproportionately affected by the coronavirus pandemic. Now, on top of that, they are trying to grapple with how they support their children and young people to access their rights to develop and thrive. At the same time, they are worrying about how they are going to pay their bills, how they are going to afford to put the specific food on the table that their children need, how they are going—just as you said—to attend appointments, and how they are going to continue to meet the additional costs they have, of which there are many.

Emily Holzhausen: I am director of policy and public affairs at Carers UK. I just wanted to corroborate what colleagues have just said. Unpaid carers, the family members, are doing exactly the same thing. They are terrified about things like petrol costs: "Can I afford to make the journey to support mum or dad?", "How do I afford that?" or "How do I help people to get to hospital appointments?"

In terms of heating or eating, it is truly distressing to see carers who are trying to make decisions about turning down the heating when they know this will have a negative impact on their own health and wellbeing—because a lot of them have disabilities themselves—or it could impact the person they care for, but they simply have nowhere to go in terms of their bills. They are also going without food to make sure that the heating stays on. For some of them, they have equipment which adds to their energy costs, NHS equipment that keeps people alive. You just cannot turn off the oxygen machines and the different tech that people have that allows them to live at home. We know that with some conditions, people have to be kept at a certain temperature otherwise it really affects their wellbeing.

The final point I wanted to make is that for a lot of these families, disability has a disproportionate impact on people's life chances. A lot of the families that we are looking at are already very close to having very low levels of savings, having no savings or being in debt. Their bandwidth, their financial resilience, is extremely tight. I absolutely agree that coronavirus and the pandemic has been really tough for families, and this really is an unexpected extra challenge on top of that.

Q2 **Chair:** Thank you. Louise, you mentioned a very specific figure of a 500% increase in the calls to your helpline. I just wondered whether any of our other witnesses had a similar sort of statistic that they could give us about what increase in pressure there has been. Regarding calls to the helpline, has that been driven by worry of bills or driven by bills themselves? I hope that makes sense.

Louise Rubin: It is really interesting. The nature of the calls we receive has changed quite a lot during the course of the year. When we first set up the service in 2020, prior to the crisis really taking hold, lots of the calls we received were about energy efficiency. What could people do to make their home more efficient? They were worried about bills, but it still felt that there was room to manoeuvre within that, so they were seeking advice on what they could do. As the year has gone on, those calls have become increasingly desperate because people have already done everything they can to make their home more efficient. They have cut back on everything they can cut back on; there is nothing left to cut back on.

They are phoning now in a really desperate state of mind looking for answers. "What else can I do? Where are there grants available? What might I be entitled to from the Government? What can I say to my energy supplier? How can I get through to my energy supplier when they

do not pick up the phone?" I would say, yes, the nature of those calls has become more worrying and the levels of debt that people are phoning us with have increased as well throughout the year. Four out of 10 callers to our service are in debt and, on average, they are about £1,300 in debt to their energy supplier specifically.

Q3 **Chair:** Salena, did you have anything you wanted to add to that?

Salena Begley: Yes. We are a grant-making charity first and foremost, and we provide grants for essential items for families on a low income. We have a high level of demand right across the UK. In England, we have had to move to families being able to apply every 15 months, whereas previously it was every 12 months. In Wales and in Northern Ireland, we have currently had to close to applications because we have already spent this year's funding. We are a charity that families turn to year after year for that vital support and we can help with so many different things that, right now, families cannot afford to cover the cost of themselves.

Just as my colleague said, many of our families used up any savings they had during the coronavirus pandemic. Many did not have many savings in the first place, but many are now unable to save even £10 a month. We are seeing extremely worrying levels of debt, and that is a mixed range of debt, including benefits debt. Over something like 26% have benefits debt, council tax debt, rates debt, but also the usual credit cards, etc. There is a high level of debt and that is increasing, and many of our families expect to get further into debt in the next six months.

Our information resources on our website try to help with the wider concerns and issues that families face. Debt is obviously one of them; energy, right now, is one of them, where they can find other grants and support. Ideally, we would like a situation where families with disabled children and young people do not have to rely on finding charitable grants in order to meet their essential needs, that the social security system would provide the buffer they need to provide for those additional costs that they have, but we are seeing families turning to us for that information and support. We try to ensure that they know where to find trusted information and support because it is a confusing landscape for families who are, frankly, very time poor.

Chair: Thank you. Emily.

Emily Holzhausen: I just wanted to support what colleagues have just said, particularly Louise. We have seen a rise across all income-related queries, and the shift, as Louise said, particularly to, "Where can I get help now?" We have had a 332% increase in, "Where can I get help with other household costs, not just energy and local authority financial assistance schemes?" We have an affiliates network of about 270 local carers organisations and local authorities, and they have all seen increases in these types of inquiries as well across the board.

Q4 **Kate Osborne:** My question is to Emily and Salena. Emily, I will come to

you first. You have already touched on how the cost of living is affecting people, but could you tell us a little bit more specifically about carers and families of disabled people, please, and also if there are any protected groups or geographical areas that it is affecting more than others? I represent a constituency in the north-east and we have the highest percentage of disabled people at over 21%, so I know that, for example, the north-east is being hit hard.

Emily Holzhausen: Thank you for your question, Kate. First of all, carer's allowance is the lowest benefit of its kind. For 35 hours of unpaid care per week, the value is £69.70 and there is an earnings limit at currently £132 a week. You can see, automatically, that is a challenge for families. There are definitely geographical differences. As you said, higher levels of disability tend to go along with post-industrial areas and areas of deprivation as well. There is a differential impact in different areas of the country and, as you said, in your constituency. There are differences between different groups of people. So, 72% of people who get carer's allowance are women. Women are more likely to be working part time as well. We are talking about smaller incomes for women, and some of these impacts will last well into retirement. They are already much more likely to have lower pensions in retirement and we are worried about the legacy that this will store up for the future.

According to Carers UK's State of Caring research, carers from ethnic minorities are struggling more. Lesbian, gay and bisexual carers from our State of Caring survey also told us they were much more likely to be struggling to make ends meet. There are some real issues here.

If we look at things like the cost of living payment going to £650 for people on means-tested benefits—quite rightly, and very important that it did—it did not go to people who just get carer's allowance on their own. We were seeing about 386,000 carers missing out on that. We have low benefits, little resilience, a gender impact, and a broader impact across some other protected characteristics. In our survey we have around a quarter of unpaid carers who have disabilities themselves. Again, this quite often comes back to people's financial resilience to be able to manage through difficult times.

Salena Begley: We recently undertook our family poll research, and 47% of those who responded indicated they were a lone parent family. We know that those carers are struggling in the same circumstances as other families, but on their own many have no family support and are struggling to access formal care outside the home, such as childcare. I would certainly agree with my colleague. We know that many lone parents are women, and we know that those women are struggling—many using terms like "fighting a losing battle"—to try to manage the resources that are available to them.

We know from the feedback from families in our research that to support them they need access to formal care outside the home, such as accessible childcare that might meet specialist additional support needs,

for example. We know that they need support from employers, and they need flexible employment. These are things that would really help many of the families that we support, including those lone parents. They need that flexibility in terms of employment, and they need childcare and formal care such as respite that will support them to undertake education and access employment where that is possible.

I read one comment from a family, a lone parent, who got two hours of respite a month and used that to study for a degree. I think that shows a level of resilience and determination among the families we support, but they need the state and local authorities to support them in their role as they try to provide the best family life for their children and young people.

Apologies, I cannot exactly remember the question but, clearly, we are supporting families, so we have a particular interest in support for disabled children and young people and their families. We are deeply concerned about the health and wellbeing impact of the current cost of living rises on their current development and future life chances and outcomes. Many have missed out on opportunities for therapy, social opportunities, even opportunities to see their families during the coronavirus outbreak. From our families' feedback, those are opportunities that children and young people rely on for their development and learning and are really being restrained by the cost of living crisis. That is on the back of the restrictions and the limitations of the pandemic. The supports they had in place before are just not there yet, and many had limited support to begin with. I know I am going off topic a little bit, so apologies, but I hope that is helpful.

Q5 **Kate Osborne:** That is great. The question was around the carers and families of disabled people and other minority groups and regional inequality. I just wondered—either of you can come in on this—whether there is anything the Government should be doing around regional inequalities that is more targeted to come up with solutions. Emily, do you want to come in?

Emily Holzhausen: I think things like boosted payments through local authorities and much more sharing of data so that local authorities are able to target funding—for example, if things like the Household Support Fund were doubled in areas. I think longer-term solutions about variable levels of benefits have been discussed in the past. That is certainly quite complex to deliver but, talking about the here and now, what is so important is to get pounds into people's pockets.

Longer term, we would like to see things like a social tariff, for example, for energy costs. That would really provide targeted help. Also, I have to say we would like a boost to carer's allowance. It really is the lowest benefit of its kind. In the future we want to take people out of poverty, especially when they are providing unpaid care which is saving the state a fortune. Over the pandemic, it was £193 billion a year, which is the equivalent of the NHS. There is a short-term issue of getting pounds into

people's pockets very quickly, and a medium and longer-term issue about structural changes that we need to see.

Q6 **Dame Caroline Dinenage:** I have a quick supplementary. I declare my interest: I am the Chair of the APP group on carers. Emily, can I just quickly go back to you? Cards on the table, I would like to see carer's allowance increased, but successive Governments have looked at this and shied away from it because of the cost.

What I am more interested in is this kind of cliff-edge at which point you go beyond a certain, very low amount of earnings when carer's allowance just drops off altogether. I just wondered whether Carers UK have done any sort of work on whether there would be any benefit from having a taper or a much more generous point at which carer's allowance drops off, and whether that might be a solution to help in the middle term with this issue.

Emily Holzhausen: Thank you, Caroline. That would be very women-friendly, talking about different protected characteristics. The withdrawal rate within the benefits system is one of the harshest penalties. At the moment, it is not pegged to the National Living Wage, so it would be a really simple measure to align that year on year with a National Living Wage of, ideally, 21 hours, but 16 hours would also be good. That would impact about 172,000 carers who currently have earnings and carer's allowance. It would just allow families to flex a bit.

Every time the National Living Wage goes up, we start to see the number of hours that carers can work fall. We have just fallen below 14 hours now, so it is about 13 hours and 20 minutes that they can work. It is such a relatively small measure but would be an indication of the change that we could really see and, certainly, allowing families to take small bits of work and stay in work.

I also wanted to add that the Department for Work and Pensions has undertaken some study on this and done some research into it, but it is yet unpublished. I understand they have not decided whether they will publish or not. I wonder whether the Committee would consider writing to the Secretary of State to see that published, because I think it would be valuable to see carers' experiences of juggling work and care and look to the future of policy making.

Q7 **Kim Johnson:** Good afternoon, panel. Emily, under the 2014 Care Act, carers are entitled to an assessment in their own right, particularly in respect of respite—that was mentioned—and to improve health and wellbeing. I just wanted to know whether Carers UK have done any assessment in terms of how well that is utilised by carers.

Emily Holzhausen: Thank you. It is a great Act, and I have to say it is really well written and has all the right objectives within it. As Salena was talking about, we really have a shortage of social care at the moment. In terms of carers' assessments, we have a backlog of all assessments, care assessments and carers' assessments. The Association of Directors of

Adult Social Services put that at about 500,000 at the moment. We have some really difficult backlogs in the system.

The number of carers' assessments has been fluctuating over the years, but official statistics have shown that the amount of support carers get as a result of it are going down over time. This is really a function of local authorities being squeezed on social care as our population has aged, and some cuts previously as well. The current levels of funding have not quite come up to that level. Carers do not really know about their rights, and people generally have trouble trying to find their way through the rights system. It is a really important gateway to support, but it is one where we need to see more investment.

I also wanted to come back to the cost of living point that you made and access to these assessments. If we provide more social care, disabled people are more able to juggle work and care; their health and wellbeing is better. Pre-pandemic, we saw about 600 unpaid carers giving up work every day. Social care can bridge some of the gap for people to stay in work for longer.

There is an immediate issue about making sure that people get the care and support they need, but also this longer-term economic issue to help people to juggle work and care is particularly important in a tight labour market, and it has a very positive diversity aspect as well.

Q8 **Rachel Maclean:** We are all aware that there are various support schemes made available by Government and local authorities. We are also aware that lots of disabled people do not take up the support. Some of the reasons might be that they are ineligible, that they are unaware or that they are deterred from claiming by some of the burden of bureaucracy. Would you like to comment on what you think are the greatest barriers from each of your perspectives?

Louise Rubin: It is certainly a very mixed picture, and it is hard to speak across the entire disabled population of 14 million people. We found, through our research, that some issues are less about people not taking up the offer but rather that the offer is not sufficient. One area in particular where this is the case is the Household Support Fund; this is often talked about by Government as a real help with the cost of living crisis, but that does not tally with our research. Of the disabled people we asked, 90% said that they have not applied—that might be because they were not eligible or because they could not face applying—but 62% had not even heard of it. It is not something that is well known, and we have had anecdotal reports of people finding it very difficult to find out what the eligibility criteria actually are or how you apply.

I would say that is probably the exception to the rule and that the majority of the support that has been made available by the Government has been taken up, but it has not touched the sides. The disability cost of living payments went straight into people's bank accounts. We asked disabled people, "Has that helped your situation?" and universally, it has

not. £150 across the whole year has not helped, particularly for that group of 300,000 people who have lost access to the warm home discount. That is a good example of Government giving with one hand and taking away almost the same amount with the other.

Q9 **Rachel Maclean:** What figure would be enough?

Louise Rubin: It is a difficult question and people are in different difficult circumstances. We hear from people who have a huge amount of equipment in their home that they need to power up, and they are looking at energy bills of £6,000 or £9,000 a year. One father who called our helpline sticks with me in particular. He has a son who uses breathing equipment, a medical bed and a hoist; in his room he has cameras and monitors for his heart. Their bills are astronomical, and what they need is very different from what others need. What we do know is that almost everybody tells us they need more, and they need it sooner. The next set of disability cost of living payments is now not due until the summer—I do not know if that means June or September, but either way, it is a very long time to wait.

Rachel Maclean: Thank you. Salena.

Salena Begley: As Louise has indicated, when we undertook our recent research, the majority of families had received the cost of living payments; when people do not have to apply for them, that obviously removes the barrier. Those automatic payments can be really useful if there is an underlying entitlement, but only 50% of those who had the payments indicated that they had helped them to manage the current cost of living, which reflects what Louise said. We had many comments from families saying how grateful they are, but it is an indication that what we really need is a system that works for our families during and after the cost of living crisis. They have been left vulnerable to the impacts of the coronavirus pandemic and now the cost of living crisis, because they do not have the social and economic supports they need to function and meet their children's and young people's needs.

As has been indicated previously, many are also managing their own health conditions along with their own child's or young person's. I do not think you can put a figure on it. It also goes back to the question about regional inequality. What is needed, as a society, is to listen to families on an individual community basis and to work with them to develop systems that actually work for them where they are at.

One of the key issues that we hear at the moment is about services that can ameliorate some of the cost of living impacts that families face, if they can access those services. If services better understood what families need and listened to families, and could apply flexibility, families would not be so badly impacted right now. It is not just about putting pounds into pockets, although families absolutely need that right now; it is also about building systems that will, in the long term, protect our families from being in such a situation again.

Q10 **Rachel Maclean:** Louise, you mentioned that your research shows that 62% had not heard of the Household Support Fund. Salena, from your experience, would you agree with that?

Salena Begley: I am sure I am preaching to the converted here, but time is a key issue for the families that we support, especially if you are a lone carer or have limited external support. Finding the time to research your entitlements or even discretionary grants is extremely difficult. There is also a fear around applying for a benefit and then being asked to repay some of it; we see relatively high rates of debt in terms of benefits. I have heard carers say they will not claim local assistance or national entitlements because they are worried that they will use that money to support their family, then a month or two later be asked to pay it back, which they know they will not have a buffer for. As Louise has said, there is no one size fits all; accessibility is key. That is a very individual thing, but there are things that we can do as organisations that make our processes more accessible to all. Apologies for the wide-ranging answer.

Q11 **Rachel Maclean:** It is really helpful, because it is obvious that you all have different people coming to you for your services. I am going to ask Emily the same question, because it seems tragic that there is help there that is not being used. If there are practical measures that can be done, then I am sure that Ministers would like to do them.

Salena Begley: I want to make one very short point; sorry, Emily. I think the third sector plays an incredible role in supporting families to access entitlements and discretionary grants. Support for the third sector is also key to local and national organisations. We have undertaken work in the past supporting families to ensure that they are getting a disability premium in terms of tax credits and similar things, because many families just did not know about it. I will leave it at that; apologies for jumping in.

Emily Holzhausen: Salena leads me on to a very good point. The Household Support Fund did not just look at means-tested benefits; it could also include payments for unpaid carers at the discretion of the local authority, and I think it was really important to build that in. I think there are 152 ways that is being distributed. Some are using local voluntary organisations and some are working from their own data systems. As Caroline has talked about in the APPG, many people do not identify themselves as unpaid carers; there is a very important job to be done to raise awareness and help people understand the role that unpaid carers play. An unpaid carer on universal credit may not know that they could be entitled to additional payments.

It is a constant awareness job. We have 4 million people across the population becoming a carer every single year and it is really important to raise awareness. The fundamental areas where we could improve are local data and knowledge about people living in local areas, and it really is essential to have these systems to be able to get payments out to people quickly. You may see lower awareness of different benefits and

entitlements in specific communities, for example ethnic minority communities. Carer's allowance is not a digitally-based benefit, but it could be in the future. That would allow you to open up a whole range of possibilities to help people understand what further entitlements there might be by pushing out information and advice. We would certainly like to see a more creative approach to that.

Q12 **Chair:** I have a follow-up question. I am not sure whether this is for Louise or Emily—maybe both. A quick answer would be appreciated, as I am conscious that we are going to have a vote at 4 o'clock.

I was at a support group for people with aphasia the Monday before last—it was a regional support group, not just in my constituency—and the point that both the disabled people and their carers were making to me was that they are entitled, in some local authorities, to a council tax discount of 25%. They highlighted one local authority, Test Valley Borough Council, where the process was quick and easy; they got their discount instantly. One carer described the experience with another local authority, Eastleigh Borough, as a constant fight to get a discount that she believed they were entitled to. There was pushback from the local authority the whole time. Then you add into that the Household Support Fund, which we know is being delivered under different mechanisms with different criteria by different local authorities. Is it commonplace for local authorities to not be helping residents get the discounts and the benefits they are entitled to, and how could central Government smooth that path? I have looked at Emily throughout, but please do feel free to answer, Louise.

Emily Holzhausen: It is really hard to answer, because I think it depends. Council tax discount comes to district councils as well as upper tier local authorities. How easy it is to get information on that really depends on the council's view. Some of it is very difficult to work through. On occasion, these things are misinterpreted, and our information and advice services quite often help the local authority translate the law. Because the benefit can be backdated, and there is no bar on how far back it can be backdated, families can be missing out on thousands of pounds a year if they do not know about this.

Where I think central Government could certainly help is in providing helpful links on benefit application processes to other things you might be able to claim. You would then start to socialise the idea that, "Oh, I could get a carer's council tax discount, or I could get this." To add to Salena's point, unpaid carers are time-poor, terribly tired and have a huge amount of worry and concern on their plate. Families really worry about getting something wrong and ending up worse off, especially when they are on tight incomes. In these cases, you sometimes have to spend longer explaining what it is and how to claim it.

Chair: Thank you. I am sorry to cut you off, but we are going to be short of time. Louise, did you have anything you needed to add?

Louise Rubin: We know there is a postcode lottery and those differences between local authorities apply across a whole range of services. We hear about it often in relation to the SEND—special educational needs and disability—system, and it certainly applies here. It is one of the reasons why it is so important that national Government are getting to grips with this crisis.

Q13 **Carolyn Harris:** Thank you, Chair. Modern medicine is a wonderful thing when it helps somebody with a disability to look after themselves at home and also work; I am thinking specifically about nocturnal dialysis, and the ability to have treatment all night and then work during the day. It is often the case that the only financial support you get towards your energy costs is through the schemes run by the hospital. A lot of these patients are not benefiting from any of these extra top-ups. How can we make sure that the Government, the regulators, and the energy companies are all making sure that everybody who needs to use more electricity and water in order to be able to continue to work and live a normal life are getting everything that they deserve?

Salena Begley: Thanks for the question, which goes back to the issues we have touched on before about general awareness of entitlement, clarity over who is eligible, and accessible systems. One of the things we did not mention earlier is the stigma that is attached to applying for benefits and discretionary grants; there should not be, but there still is. Removing barriers such as inaccessible systems and the confusion around entitlement is rather a nuts-and-bolts answer—it is not very highbrow—but families need things to be as straightforward as possible. They want these things to be seen as a right, rather than something that they need to go cap in hand for, because their children and young people need these things to survive, to be healthy and to develop.

There are a number of factors that would be really helpful, including ensuring that people are not having to search for hours to find out about entitlements and that there is a clear pathway to information, for example, from the hospital. Again, this should not rely on there happening to be a specialist charity or service. It should be built into the system that families of children and young people with particular conditions are made aware of the support, and that should also apply to adults. Building in a rights-based approach to these supports and entitlements would be a good start.

Louise Rubin: A different answer from us: perhaps the ultimate solution to that is the establishment of a social tariff for energy. Many of the solutions that have come so far from Government have been quite universal in their approach; we all benefited from the £400. We now need something that specifically targets those who need it most: the disabled, people on low incomes, and carers. We feel that the social tariff that takes into account your income is what Government ought to be focusing on next, particularly when the price guarantee comes to an end next year. This would particularly benefit people who are on means-tested

benefits and entitled to PIP and DLA but also people who need to use more energy because of their condition or their impairment. This group are really in danger of being left behind at the moment as they do not qualify for means-tested benefits, but they are still facing huge energy bills. There are no real solutions being put forward for them at the moment, and we thing that a social tariff that provides a discounted energy bill could be the answer.

Q14 **Carolyn Harris:** Kidney patients are often in that category because they are able to work. Emily, do you wish to add anything?

Emily Holzhausen: I agree 100% with Louise, and Carers UK is very supportive of what Scope has put forward on social tariffs. I would add that there is a role for the NHS around personal budgets if there is specific equipment. This may be on top of social tariffs and involve moving more care into the community. The family that Louise was describing earlier would be a good case in point. If people are having to pick up more health tech costs, we should be looking at really responsive, tailored personal budgets, because you really need both.

Chair: That brings us to the end of our first panel. I thank the three witnesses for taking the time to speak to us. We will now suspend the meeting whilst we bring in the second panel.

Examination of witnesses

Witnesses: Jignesh Vaidya, Abigail Broomfield and Suzanne Buckner.

Q15 **Chair:** I thank our next panel of witnesses, Suzanne Buckner of Carers UK, Abigail Broomfield, who created the petition—which Cat McKinnell has certainly written to this Committee about—and Jignesh Vaidya from Scope, for taking the time to speak to us today. I will start with a very general question and ask Suzanne first. Could you tell us a bit about yourself and the extra costs that you have encountered associated with your caring responsibilities, please?

Suzanne Buckner: My background is rather diverse. I have run several companies, including an advertising agency and a trade association. I also set up a special needs school for comorbid children. My caring role began when I met my husband, sitting behind me, who has clinical depression and a personality disorder. Our son was born in 2000 and has severe behavioural problems; he has a diagnosis of autism, ADHD and ODD. I also have my charming daughter, who is sitting behind me, who was diagnosed with neuroblastoma in 2007. Subsequently, she has very complex and difficult medical needs including being deaf and she has five tumours in her liver. She has non-autoimmune type 1 and type 2 diabetes and total ovarian failure. She is asplenic, atrophic and has severe back problems due to radiotherapy where her vertebrae are growing into her discs. I also cared for my mother who had a tracheotomy and bronchiectasis; I did some very old-fashioned nursing,

which was a privilege, on an old-fashioned ward sister, including toileting and so on.

The costs associated with caring are going up exponentially. I have to make choices as to whether we will travel to Birmingham for hospital visits or whether we can do a Zoom call with Lottie's consultants. Lottie's body temperature runs lower than normal because of the treatment she had, which means we have to keep the heating on. She has extra costs for medicines that you cannot get on the NHS—or they have failed to provide—along with additional treatments, like osteopathy. Those costs are going up exponentially, because there are extra gas and electricity costs involved. Our gas and electricity bill has gone from £123.26 in April 2022, to £279.32 a month. A tank of diesel has gone from £80 to £110 over the course of nine months and our food bills have gone up 20%, partially because Lottie has to have a specialist diet to keep her healthy. We just have to take those costs; it is huge, indescribable.

Abigail Broomfield: I am disabled and a full-time university student. I set up the petition calling for all people on disability benefits and carer's allowance to be automatically entitled to the £650 cost of living crisis payment. We hit just under 25,000 signatures when the petition ended in December 2020. I did not have a team around me working on that; I set it all up myself through campaigning.

I have multiple conditions which impact me, both physically and mentally. As a result of this, I need to have a constant temperature; I cannot have it either too cold or too warm in my little studio flat. This is very much a constant battle as otherwise my conditions are aggravated. I use a lot more water than the average household because I have to shower to help keep my temperature regulated, and I go through a lot more washing due to sweats and other conditions. I often rely on taxis as I cannot walk too far, and the cost of that has gone up. I have to pay privately for some of my therapy as there are now waits of up to two years for mental health. Even then, you are only entitled to a set amount of weeks, which for someone with complex trauma issues or complex mental health needs is simply not enough.

I have special dietary requirements and the costs for those foods is ridiculous. I have had to purchase specialist equipment. I have a wheelchair I use on my bad days, and I also rely on electricity for electric blankets and heat pads to help me with my temperature and chronic pain. I do not have enough money to hire carers, so I rely on family and friends. I do not have gas in my tiny studio flat—it is three tiny rooms—but my electricity bill in January 2022 was £53; the cost in December 2022 was £166. My taxi costs have increased between 50% to 100%. Bus fares have also increased if I am well enough to get a bus, which I am very rarely able to. My therapy costs are increasing from April, but that has not been announced yet, so I do not know if I need to reduce it. Laundry costs have increased by 40%.

I speak to many others in the disabled community through my campaigning work related to the petition, and some people's costs have increased by 400%. They are going without equipment like electric wheelchairs. One person told me that their feeding pump stopped working due to the cold weather and the fact that they were not able to heat their house. It is very bleak.

Jignesh Vaidya: I am Jignesh. I am a wheelchair user who had polio at the age of two. For me personally, I have had to give up my daily activity of going to the gym—I was quite a regular at the gym—because I could not afford it. Secondly, because of my polio and all the severe weather we are going through, I need to leave the heater on a lot of the time. I became a father 14 months ago, but my condition has meant sacrifices for my family. They have to put two heaters on in the space I am in right now in the kitchen. In the living room, they have nothing. As soon as I finish, we switch, they turn the heater on, and I turn the heater off and put the blanket on my leg. I have also had to give up my basketball activities, which I used to do two or three times a week before the crisis started. I now go monthly if I am lucky enough to save some money and afford the fuel prices. Those are just a few examples.

Chair: Thank you very much.

Q16 **Kate Osborne:** We have heard from our first panel and from you that there are additional costs that come with being disabled. A phrase that was used quite a lot was that the choice is between heating and eating. I know from my constituents that often there is now no money to do either, let alone one or the other. What everyday choices—or, more accurately, sacrifices, have you had to make—or are you still making, to keep up with the cost of living crisis that we are in right now? Suzanne, can I go to you first?

***Suzanne Buckner*:** It is very simple; it is whether we turn the lights on, whether we turn the washing machine on. As I said previously, I have to ask hospitals whether we can postpone or make visits via Zoom. It is crippling in terms of how you are going to feed, clothe and transport. Sometimes it can become completely overwhelming. My husband cannot work due to his disabilities. I do not, unfortunately, have any extended family, so I get no respite. As I have said, I have extra heating costs for Lottie and she needs a specialist diet. Petrol is a high consideration. If Lottie goes into hospital, food in the hospital is expensive and then I have to leave meals at home as well, so I have double the cost. Fortunately, I do not have a mortgage because my mother died having contracted hospital-induced pneumonia via the NHS. Thankfully, she left me an inheritance. If I did have a mortgage to consider, I am afraid we would be placing ourselves in the hands of the state for you to care for our family.

I do not think that local authorities—who you devolve your power to—really engage with the communities they are meant to look after and understand the issues which they could help with on a day-to-day basis.

It not only affects me dramatically, but it affects my family even more. My son can become physically violent towards me if I have not got money to give him. My husband literally closes down, and my daughter becomes suicidal. My daughter loves animals, and we are considering whether we have to get rid of some of them. It is pretty dire at the moment.

***Abigail Broomfield*:** At the moment, I am only heating one room, the main room I spend most of my time in. I am not alone in doing this; there are other disabled people doing the same. One of my friends ended up in hospital because she only heated one room and she got hypothermia. This was during the cold spell in December. Fortunately, she is still with us, she came out of hospital just before Christmas. That is the reality. We are heating one room. I am not switching my lights on. I use a torch, which, with my mobility issues, is a fall risk. I am putting myself at risk of hurting myself just to try to save a few pennies because, as I said earlier, my bills have jumped by over 300%. I am also having less food because I cannot get the cheaper value food any more due to the cost of living crisis pushing those who were previously able to afford more into buying the value range foods. Period poverty has come back for me. I have had to change what I use for menstrual products and go for lower quality items. I am not seeing my friends or family as much as I used to. As a really social person, this impacts massively on my mental health. I have given up my hobbies, I have worn layers. If I get through this winter, I feel like it will be a miracle. During that cold spell in December, I actually saw my breath when I was in the bathroom as my flat was so cold.

We are making a lot of choices between heating and eating, and, as a result, we are pushing ourselves into debt with utility companies because we have to choose food to stay alive rather than paying these companies that are charging us such a large amount.

Q17 **Rachel Maclean:** I am sure all of us are finding this evidence really very difficult to listen to, so thank you all for coming. Can I ask you how supportive you have found the energy companies if you have approached them for any kind of help or access to any special payment schemes, or sources of support or funds? I will start with you, Jignesh.

***Jignesh Vaidya*:** I was told the money will go straight on energy. I still do not know how much they are willing to pay, but last time I paid the bill, it was £149, and I thought it was being directed to monthly, but so far, I have no idea how much the Government are giving me or what I am entitled to. I have two different jobs; I work from home and go to the office one day a week, so my income is limited. Whenever I apply for something or try to get the funding, I never know what my entitlement is. Every time the energy company just say, "Oh yeah, do not worry. We have got the reference number. We will find out and come back to you." Then I get a letter now and then saying, "Yes, you are entitled, we will get back to you," and that never happens. It is really unclear. Some

people easily take advantage of disabled and vulnerable people, just approaching us and never coming back to us.

***Suzanne Buckner*:** Our water company has a vulnerable tariff and they have been quite helpful, but our gas and electricity company has not helped at all. Although we are registered as vulnerable customers, they recently cut the power off and the next day sent me a letter telling me that they would do this on a regular basis because we had to save the National Grid, even though our power came on at the same time as everybody else. With regard to a telecoms company—we are with a well-known British provider—their packages for disabled people mean we would have such limited access, because we live in the countryside, that it is hardly social because I would not be able to contact anybody. In a nutshell, not very helpful at all.

Q18 **Rachel Maclean:** Can I pick up on what you just said? I understand there is a scheme, the Priority Services Register, which is supposed to protect against power cuts and that sort of thing. It is the first time I have heard of it, which probably indicates some of the problems that our witnesses were mentioning. Have you heard of this scheme?

Suzanne Buckner: Yes, we are on it. We are registered as vulnerable customers. I actually have the letter that was sent to us the next day telling us that they would be turning off the electricity to protect the National Grid.

Q19 **Rachel Maclean:** It is supposed to give you priority support in a power cut or emergency.

Suzanne Buckner: True, and I get a text to tell me that I am a vulnerable customer and people that live with me are vulnerable, and the electricity goes off and I get the candles out and the torches like everybody else, and then I get the letter. We are on the register, but it does not work.

Q20 **Rachel Maclean:** Which company is that?

***Suzanne Buckner*:** Scottish—

Q21 **Rachel Maclean:** Are we allowed to say that?

***Suzanne Buckner*:** Am I or not?

Chair: You are.

Suzanne Buckner: Okay. Scottish Power.

Rachel Maclean: Scottish Power, if you are listening, do better.

Suzanne Buckner: Yes, I would agree.

Q22 **Rachel Maclean:** That is disappointing.

Abigail Broomfield: They have not been supportive at all. I had to sign myself up to the Priority Services Register and do my own research to find out about it even though I had been in contact with my energy provider since January last year, when I moved into my current flat. I have had to take my energy provider to the Ombudsman because they have repeatedly ignored me when I told them I cannot do my own meter readings and I cannot ask carers to read meters for me because they are down two flights of narrow stairs in the basement. There is no way I can do that with my mobility issues, and I do not want to risk injuring others. I am currently taking my energy provider to the Ombudsman because they ignored me when I told them, "I am disabled, I cannot do this." It was only when I signed myself up to the Priority Services Register in July 2022 that they started to come and do my meter readings for me. I have all the proof. I have sent emails, I have made phone calls and they have just ignored me. They were more interested in trying to install a smart meter than assisting me.

I was also late paying a bill when I was able and in the position to pay earlier last year. My small debt was less than £200 and they sent it straight to a debt collector and were chasing me with phone calls. At the moment, I am having to block it out because otherwise it will severely impact my mental health. With my water bills, water companies have been a bit more flexible. They have set up a direct debit reasonable amount. There is no awareness of support, and there is no contact from companies either. With the Priority Services Register, I just got a text to say, "You are on the Register" and that is it. We do not get anything else. As I said, I had to find that and sign up myself because nothing was offered.

Q23 **Rachel Maclean:** What is the power company where you had to set this up yourself?

Abigail Broomfield: It is Bulb.

Rachel Maclean: Okay.

Abigail Broomfield: Yes, it is currently going through many transitions.

Q24 **Rachel Maclean:** It is. Which company are you with, Jignesh? You said that they were poor as well.

***Jignesh Vaidya*:** I am with E.ON.

Q25 **Rachel Maclean:** None of them have a good record, do they?

Jignesh Vaidya: No. I had the same thing as the other panel member, text messages saying, "You are on the priority register as a wheelchair user." With the electric company, nothing. It is like a mirror image of what the other two panel members said. Maybe they are working secretly together.

Q26 **Dame Caroline Dinenage:** Thank you all for coming to share your

stories with us today. You are very brave, and we are really grateful to have you here. Can I ask, do any of you receive any benefits or other government support? If you do, to what extent does that go towards meeting the costs that you incur? Suzanne, I am going to start with you because I have made eye contact with you, so you are on my radar.

***Suzanne Buckner*:** I receive universal credit of around £972 per month after my carer's allowance of £69.70 per week is deducted, so in fact I care for three people totally for free. If you earn more than £132 a week, as Emily said earlier, your allowance is also deducted. There is no incentive for the mid-fifties they are trying to target to go back to work. Because I am on benefits, I cannot get credit. When I was trying to pay my mortgage and was in mortgage arrears, I could not re-mortgage because I had no income. Cash then becomes incredibly important. At the moment, nobody wants cash to continue as a method, but it is very important when you are in a deprived situation. Mark and Freddie get personal independence payments and Lottie gets disability living allowance. This goes towards paying some of the costs for medicine and treatment for Lottie.

I have to say, could any of you actually manage on £972 pounds per month? If you knew my background, I got considerably more than that, I can assure you. If I had not fought the local authority to get a direct payment so I can transport my children to their places of education, we would not be able to pay the gas, electricity, TV licence, phone, food and fuel bills. I cannot borrow money as I have no close family and, as I said, my mother is now deceased. I have had to use food banks, believe it or not. I do not sound like it, do I? The Government, in my opinion, is trading on relatives' goodwill to care for people when it is the state's duty of care. What if we went on strike? Going by Parliament Square today and seeing everybody on strike, including the teachers, I felt like getting out of the cab and getting a placard, I really did. It was tempting, but there we go.

Q27 **Dame Caroline Dinenage:** Lots of carers feel the same way, Susan. Thank you. Can I go to you, Abigail?

***Abigail Broomfield*:** I receive no means-tested benefits. I receive contribution-based ESA, which is £230 every fortnight. I am only entitled to the standard rate of personal independence payment, which is £335 every four weeks. I do get the student maintenance loan, which I get every four months and nothing over summer. That is going to end this year unless I am successful in going into postgraduate study. When all the cost of living crisis support was announced in May last year, the media spun it that everyone was going to get all this support. Actually, all I was entitled to was the £150 payment, which I got for being on the standard rate of PIP. Currently I am not sure if I will be continuing to get PIP because I have been under review for that since August last year. I have just have a text saying, "We have got your paperwork, but we don't know how long it is going to take." I was excluded from the uplift that was put in place during the pandemic. I was excluded from the £650

payment. It is a huge struggle to actually get disability benefits. The whole process is dehumanising. It made me feel awful. You have to get so much evidence, and it is so stressful. It takes months to get the ball rolling. You have to give in all the paperwork and then someone who is not medically trained, or is not aware of your conditions, says, "Actually, I think you are only entitled to this bare minimum." It is just disgusting. I am trying really hard not to cry as I talk about it. It just makes you feel worthless.

I have so much uncertainty about my future. If I am only entitled to what I get currently, and I do not successfully get onto a postgraduate degree, I will be living on less than £800 a month. As I said earlier, my electricity bill last month was £166. My rent has gone up to £430. There is just simply no way I am going to be able to survive. It is horrible having to rely on my mother, who is a carer as well, not for me but for my disabled stepdad. She has to give me some of her earnings, because she is also a carer in a care home. She cares 24/7 for absolutely everyone. I should not be having to ask her, "Can I have some money for food?" Accessing food banks is not easy either. You need to have referrals, which not everyone gets. I do not have a social worker who can refer me. I do not have that support. It is just very difficult to access any help.

***Jignesh Vaidya*:** I receive disability living allowance. I use that to get my Motability car, which gets me to work when I go to work, or when I used to do basketball training or attend the gym. I also get tax credits as well because I am on a low income. I use that money to buy fuel to get me from A to B or sometimes I ask a family member, "Can I borrow some money?" In my case, it is my mother, who is 82 years old. Now and then I ask her, "Mum, please, can I borrow some so I can go to training once a month?" That is the only benefit I receive.

Q28 **Dame Caroline Dinenage:** Just to recap, to what extent do you think the benefits cover your costs, and where is the shortfall?

***Jignesh Vaidya*:** I am working full time. I thought I might get more money through tax credits because I am only getting £21,000 or just about £22,000 from my two jobs. I thought, if I am working hard, the Government might say, "You get more tax credit," to make it £25,000, but it does not. It did in the past, but all the rules and regulations were changed.

I am dreading what I am going to do next. Am I able to go out and socialise with a friend, or go to basketball? That was my one and only output, to see my other friends who are disabled like me and play sports together, but that has now been taken away. I will maybe see them once a month if I am lucky and if I can afford that.

Q29 **Kim Johnson:** Thank you so much for providing us with some very personal and painful testimonies today. Abigail, I just wanted to pick up on what you said in terms of ESA. We know that ESA is classified as a legacy benefit, and those on legacy benefits did not get the £20 pound

uplift that so many did during Covid. Some disabled benefit claimants took the DWP to court recently, but sadly failed. What do you think the Government should do to recognise some of those issues?

I also wanted to ask you a question about PIP assessment. As a constituency MP I get lots of emails from constituents who say that they have undertaken a PIP assessment, they have been denied and have to go to appeal, which is a lengthy and traumatic process. Then they eventually win, but they have been put through a very difficult situation. What should the Government be doing in terms of awarding contracts to people who do not have the relevant experience to undertake an assessment?

***Abigail Broomfield*:** If we talk about the ESA first, I get the contributions-based employment support allowance, because I was able to work before I went back to university to study. I worked about 15 hours. I have spoken to some people who were part of that legal action, and I think the Government should repay that uplift amount for those who were on legacy benefits, because we have so many challenges to face. Even entering the building today was a challenge.

Turning to PIP, I started the whole ball rolling in March 2020 because I got made redundant from my job. I was struggling to cope with my studies. I was also in a violent relationship and was experiencing domestic violence, so I had to start sorting my own benefits out. It was not until September 2020 that I had my assessment. In October I was told I was entitled to the standard rate, and I did not take it to appeal because I was just so burnt out and worn out. I had no money from March to August, when I got my ESA, other than my student loan, which runs out—*[Interruption.]*

Chair: I am sorry, but because of the Division, I am going to have to bring the meeting to a close. Can I just thank all of our witnesses for the evidence you have given today? I appreciate that it has been incredibly difficult for you.

***Abigail Broomfield*:** I had a whole list I wanted to go through as well.

Chair: If there is something you wish to submit to us in writing, we are always happy to take that. I apologise, but because of the Division we have to go and vote.