# Select Committee on Economic Affairs

## Corrected oral evidence: Social care funding in England

Tuesday 4 December 2018

4.30 pm

Watch the meeting

Members present: Lord Forsyth of Drumlean (The Chairman); Lord Darling of Roulanish; Baroness Harding of Winscombe; Lord Layard; Lord Tugendhat; Lord Turnbull.

Evidence Session No. 5 Heard in Public Questions 42 - 50

### Witnesses

I: Dominic Carter, Policy Manager, Alzheimer's Society; Kari Gerstheimer, Director of Information and Advice, Royal Mencap Society; Tracey Loftis, Head of Policy and Public Affairs, Versus Arthritis.

# Examination of witnesses

Dominic Carter, Kari Gerstheimer and Tracey Loftis.

Q42 **The Chairman:** Mr Carter, Ms Gerstheimer and Ms Loftis, welcome to the Economic Affairs Committee and thank you for agreeing to start a little early. We have just concluded one report on the retail prices index and, as you know, we are now conducting an inquiry into social care. I begin by asking you about the current social care system in England and your experience of how it works for the people whom your charities support. Can you perhaps also give us some indication of the extent to which you expect demand for social care for adults between the ages of 18 and 65 to increase, and what effect this will have on the funding needs? Who would like to go first?

***Dominic Carter:*** I am very happy to. I am from the Alzheimer's Society, which represents 850,000 people with dementia across the UK. We expect that number to increase to 1 million by just 2021, and for those people the social care system just does not work. We hear from people who come through to our helpline and from our call-outs on media channels that there are serious issues with different aspects, relating mainly to the cost and quality of, and access to, support. People with dementia find it very difficult to access care in the first place. Many with mild and moderate symptoms, which can still be quite debilitating, find that there is no offer for them whatever.

**The Chairman:** I am very sorry but this building needs refurbishment. I do not know what the noise is but it sounded like a kettle boiling.

***Dominic Carter:*** Someone's tea is about to be ready.

**The Chairman:** Apparently we have lost our water in the Palace of Westminster. Please continue.

***Dominic Carter:*** There is really quite a big challenge in access to support. For people with dementia who can access that care, it is often extremely expensive. We find that they often pay up to 40% more for the care they receive and that costs for it are typically around £100,000, often significantly more than for people without the condition. When you can access and pay for that support, its quality in dementia care is such that more than a fifth of services are rated as failing by the CQC—a higher fraction than for everybody else. Generally speaking, the system is collapsing when more people are expected to need it. There are people living with dementia aged under 65, and that number is growing. We find that there are few services available for people in that age group and that they often face significant challenges with support to continue working and with ensuring that their care is there. A lot of this pressure falls on family carers from all age groups. We are seeing more and more people who need support between the ages of 18 and 65 growing to an older age, and therefore many more developing dementia and needing help.

**The Chairman:** Would you be able—not now—to provide the Committee

with some kind of breakdown on the distribution according to age?

***Dominic Carter:*** Absolutely, yes.

**The Chairman:** Perhaps we can have Mencap next.

***Kari Gerstheimer:*** Thank you for inviting me. Mencap is the national charity for people with a learning disability but we are also a social care provider, so we speak for the 1.4 million people who have a learning disability in the UK but also for the 5,000 people who receive a service from us. Of those 1.4 million people with a learning disability, only 178,000 are in receipt of publicly funded care so 1.2 million people do not receive it. It is by no means the case that all those 1.4 million need care, but our position would be that it is certainly a lot more than 178,000 people. For the people receiving our services, 93% of our services are rated good or outstanding. We know that we can offer a good quality of life to the people who are in our services, but that is often despite the system rather than because of it.

For many of those 1.4 million, the social care system is not working and, as Dominic has already highlighted, that has a significant impact on carers. But it also has a significant impact on other parts of the state infrastructure, so too many people with a learning disability end up in the criminal justice system. Indeed, 30% of young people in custody are said by the Prison Reform Trust to have a disability. That is having a profound impact on those at either end of the needs spectrum when it comes to learning disability. If we look at those at the lower end of need, they are dropping out of the social care system altogether. On our helpline, we are seeing people refer into us as street homeless. People are falling vulnerable to pimps and those who use and sell drugs in their homes. Then if we look at the other end of the spectrum of need, many people with a learning disability have behaviour that challenges. I am sure that the Committee is aware of the *Transforming Care* agenda, under which people with challenging behaviour are ending up in assessment and treatment units. The UN rapporteur for people with disabilities has recognised that enormous human rights abuses are happening in assessment and treatment units.

The Government themselves have recognised that people should be treated in the community. Under the Government guidance in *Building the Right Support*, the target was to close 35% to 50% of beds by March of next year. It is widely acknowledged that NHS England will fail to meet those targets.

We know that there is a lack of funding. I am sure the Committee is aware that there has been an estimated real-terms cut of £6.2 billion since 2010 to social care funding. It is fair to say that that dramatic reduction in funding, which has happened against a backdrop of growth in need, is leading to local authorities acting unlawfully. You may well have seen that within the last week, the Local Government Ombudsman said that the number of complaints has risen by 50% and that the uphold rate has increased from 42% to 62%. We see the same thing on our

helplines; the number one reason for people calling us is social care and in about 40% of cases, the person calling has either been told something unlawful or been subject to an unlawful decision, so it is fair to say that something is deeply wrong with the system.

You asked me about the growth in need and how many people of working age there are. Within our system, as a provider we support 400 people aged zero to 25 and 2,500 aged between 25 and 50. In the UK as a whole, there are 863,000 adults with a learning disability who are of working age and 726,000 of them are in England. By 2030, it has been projected that numbers will grow by 10%; that figure has come from Professor Emerson at Lancaster University. The reasons for that growth include that, as the rest of the population ages, more people with a learning disability are living longer. More people with complex needs are also surviving longer into adulthood than previously, due to medical advances. It is also thought that the number of babies with complex needs born in Asian communities is increasing. Funding is not keeping pace with that growth in population so there is a growth in numbers and in need, but no growth in funding.

**Lord Tugendhat:** Can I clarify one point? I am not sure that I kept up with all the figures but if I understood you correctly, you say that there are 1.4 million people with learning difficulties and, subsequently, that 78,000 are in receipt of social care.

***Kari Gerstheimer:*** It is 178,000 in receipt of publicly funded social care.

**Lord Tugendhat:** Yes. Are the reasons why they are in receipt of publicly funded social care directly related to the fact that they have learning difficulties, or do they have problems which people who have no learning difficulties might also have?

***Kari Gerstheimer:*** I am afraid that I could not give you an analysis of that data but, in general terms, people with a learning disability qualify under the eligibility criteria for receipt of social care on its own. Of course, there will be people with a learning disability who also have other needs. Does that answer your question?

**Lord Tugendhat:** Sort of. As you put the two figures together, it seemed to me that at least some of those 78,000 might be people with physical problems which they might just have easily have had if they did not have learning difficulties.

***Kari Gerstheimer:*** Yes, that might be the case.

**The Chairman:** Ms Loftis?

***Tracey Loftis:*** Versus Arthritis is the UK's largest national arthritis charity and dedicated to pushing back against the impact of arthritis. That means we fund research and campaign; we also provide information and support. The overall burden of musculoskeletal conditions—please pardon me if I use "MSK conditions" rather than "musculoskeletal" throughout this session—means we are talking about the largest cause of

pain and disability in the UK. There are 17.8 million people living with rheumatoid arthritis, osteoarthritis, back pain and fragility fractures, which are hip fractures from a standing height.

**The Chairman:** Did you say 17.8 million?

***Tracey Loftis:*** Yes, 17.8 million. This has substantial impact on a person's life. It causes pain and joint stiffness, along with functional limits to dexterity and mobility. This makes everyday tasks that we all take for granted, such as even putting on our clothes, cleaning and doing housework—all the basics of life—more difficult. What makes it even harder is that the impact of arthritis is sometimes not recognised, so we are missing out on opportunities to ensure that people have good health and well-being, and can flourish.

Survey data from people with arthritis has told us that one in two are having either none or only some of their social care needs met. The impact on them means that they are living with fatigue and in isolation, and seeing their health deteriorate. They also rely more on friends and families. The extent of this is such that one in four struggle with some of the basics, such as cleaning and bathing.

When we look at aids and adaptations around the home, which could be anything from a grab rail to a toilet seat raise, form the number one issue that people phone our helplines about. Yet when we look at the system, it is not working as it should be. People with arthritis have told us that aids and adaptations improve their quality of life; 95%[1] have said that these can have a positive impact. They can also impact on their independence and, crucially, 15% of people with arthritis have said that they can help them maintain independence, which means that they could stay in their home rather than go into a care home. The challenge that we have found is in information and access. Clearly, local authorities have a duty to provide information about aids and adaptations, yet people struggle to navigate the system.

What people also struggle with, even if they have eligible needs, is actually accessing the very things that could help them. One in two people with arthritis whom we surveyed were buying equipment for themselves and only a small minority were getting those things from the local authority. There is a lot more that could be done, including a role for the Department of Health and Social Care to provide best practice guidance to ensure that we spread quality and best practice across the piece.

Moving on to your question about age distribution, there are about 6 million people in the UK living with arthritis over the age of 65, but there are 11.8 million people living with the condition who are under 65. One thing we are conscious of is that some of the risk factors for musculoskeletal conditions are ageing, obesity and physical inactivity, so we expect the prevalence to become greater in the future. The Committee may also be aware of the work of Professor Carol Jagger in Newcastle. She has estimated that the prevalence of arthritis[2]may double

[1] Witness correction: 95% of those surveyed
[2] Witness correction: among those over 65

between 2015 and 2035. When talking about the need for social care, the situation becomes somewhat more complex because arthritis can affect people in different ways. It could have a mild or a severe effect.

We are struggling with a slight lack of data here but if we use some proxy indicators we can say that among people with rheumatoid arthritis, which is some 400,000 people across the UK, about one in four[3] have told us that they have had to give up work. Clearly, we are looking at people with severe needs in the working population, who ideally we would like to benefit from being in work. If we look at people living with osteoarthritis and who may need a hip or knee replacement, which is about 210,000 people across the UK, after having such an operation they clearly may need rehabilitation but also help within the home to get back on their feet again.

**The Chairman:** Thank you very much.

Q43 **Lord Darling of Roulanish:** I want to ask about how we might meet these problems, in particular what views you have on how the care that is needed should be provided, financially as well as materially. There are two parts to my question.

What do you see the solution as? For example, I think the current Secretary of State for Health has indicated that in talking about care for older people, we should be paying a 1% increase in national insurance over the age of 40. Others have talked about hypothecated tax or various degrees of "free" care and so on. It would be helpful if I could get a view from you on what you think is the solution to the funding issue, but, equally importantly, on what we ought to be paying for.

Listening to each of you, particularly Tracey Loftis's point, it strikes me that there is a huge spectrum of the assistance or care that someone might need. Whereas we pay through general taxation for the NHS and people generally understand the principle behind it—if something is wrong with you, it will do its best to fix it—when you are dealing with care it covers a huge range, from people who really need residential care for long periods to those who need adaptations. Also, some of what we are talking about comes from central Government but a lot comes from local Government, where in many places it is something of a lottery as to what you get. I know that is a big question, but we have set ourselves a task and are supposed to come up with the answer to some of it.

How do we fund it, what model would you propose and what would the contract be? That is: if you paid this, what would you expect to get for it? I do not mind who goes first—whoever has the answer.

***Tracey Loftis:*** Our starting point is looking at which principles a new, reformed social care system should be built around. We certainly share the view of the Care and Support Alliance on some of its principles. First, it is about ensuring that is person centred and that an unmet need is met. You have clearly heard some examples of this already. From our perspective, we have heard of examples such as Catherine, who lives with rheumatoid arthritis in London and is in her 30s. She waited 16

[3] Witness clarification: One in four surveyed

We must also make sure that risk is spread across society and is not a burden placed on any one group. If you look at the prevalence of people with arthritis, a greater proportion of people living with arthritis come from more deprived communities compared with the more affluent. So we need to think about how we can ensure that it is based on what people need.

**Lord Darling of Roulanish:** If I can stop you there, I understand that, but tell me how you would do it. Is it general taxation?

***Tracey Loftis:*** Versus Arthritis does not have a specific recommendation on how to fund the system. We have focused more on what principles the system should uphold.

**Lord Darling of Roulanish:** If you have a principle that it should be spread, which I perfectly understand, that takes you to taxation.

***Tracey Loftis:*** That is one answer. We have not gone so far as to make a specific recommendation.

**Lord Darling of Roulanish:** Do you know of another one?

***Tracey Loftis:*** You make a very good point.

**The Chairman:** You are beginning to sound like a politician.

**Lord Darling of Roulanish:** Similarly, if we take your example of someone who waited 16 months before anyone turned up to do what was necessary, that might be a money problem or a general staffing problem for local authorities or it might be the fact that some local authorities are not terribly well organised.

***Tracey Loftis:*** This is why we are conscious that there is a social care funding gap in local Government. The Local Government Association has talked about a £3.5 billion gap. We are also conscious of the need to learn from best practice in areas where there are high-quality services.

***Kari Gerstheimer:*** We would be supportive of an over-40s tax.

**Lord Darling of Roulanish:** What would that pay for?

***Kari Gerstheimer:*** Our position is that a dramatic intervention is needed. The system is dramatically underfunded and a bold solution is needed. We applaud the DHSC and the Secretary of State for suggesting quite a brave approach and respectfully urge opposition parties to engage meaningfully rather than treating social care as a political football.

The CSA has seven tests. The investment of short-term funding is critical to prop up a social care system that is at risk of failure. The sleep-in back pay issue is hanging over what is already a precarious system. Then we

need a sustainable long-term funding solution that shares the costs of social care fairly across society. Fairness is quite an important question and something that society needs to agree on. "Fair to who?" is quite an important question. Intergenerational fairness is obviously critical—fairness to working-age disabled people as well as older people. Fairness geographically is also really important. Cordis Bright has done some research recently that indicates that one of the biggest factors in access to quality care is where you live. We know already that the council tax precept and the business rates funding solutions just will not cut it because they have an impact whereby they disadvantage already-poor neighbourhoods.

The Citizens' Assembly on Social Are was commissioned by the Health and Social Care Committee. About 50 people—chosen at random but including representatives of different age groups such as working-age disabled people and older people, and carers' groups—were given information and trained by an expert in social care. When they were given all that information it was really fascinating that they voted overwhelmingly for more tax, and for all social care, not just personal care, to be free at the point of the need. "Access to what?" is a really important question. If you look at eligibility under the Care Act, currently there is no hierarchy of need. It is important to recognise, for people with a learning disability, that some of that care which enables you to get out into the community, rather than delivering—

**Lord Darling of Roulanish:** I fully understand that, but what I was trying to get at is that if you want to sell a proposition to the population as a whole—which is rather different from a group that has been subjected to an hour's tutorial on what their needs are—and the proposition is, "You will pay a penny more on your income tax", their obvious question will be, "So what do I get?" As I said earlier, with the NHS you know roughly what you are going to get. Most people are happy; some people feel they should have got more, and so on. I understand that. What I was trying to get from you is: to what extent is there agreement on—or to what extent do you have views on—"If I am paying my extra penny, what would I be getting that I would not be getting today?", other than, in general terms, there is more money in the system and you might hope it would filter down to what you particularly needed?

***Kari Gerstheimer:*** Absolutely. The lack of awareness of what social care is, is really critical. Any public conversation about social care needs to start with education because a third of the population do not even realise that social care is not part of the NHS free package. Quality is really important. Universal access is really important. Obviously, the funding envelope will never be bottomless but we need to recognise that currently too many people—older people and working-age disabled people—do not receive care. Greater eligibility and higher quality are what should be delivered.

**Lord Darling of Roulanish:** That is still pretty general, though.

***Kari Gerstheimer:*** The starting point would be the current eligibility criteria. The eligibility in the Care Act is pretty generous. The problem is that it is not being applied properly.

***Dominic Carter:*** The Alzheimer's Society supports the concept of risk-pooling. We would support something which looked at an age group above 40 to consider intergenerational fairness. We polled the public to ask them what they would feel about paying more income tax, and more than half were supportive of that notion, providing of course that it went on dementia care and they would actually get something back. At the Alzheimer's Society we feel this is a crucial part of solving the puzzle for the public, in that there is a growing and angry understanding that if you develop many different conditions you will get free support through the NHS, but if, like many, you develop dementia most of the responsibility for paying for care will fall on you and your family, meaning that of the £26 billion that dementia costs every year, two-thirds is being shouldered by the individuals concerned. If we are able to have a national discussion around the concept that one in three people born today will develop dementia—as colleagues on the panel and in other organisations and charities will highlight—we believe that the third sector and charities will be key in bringing the public along with us.

Looking at the kind of energy behind social care at the moment—the very fact that we are talking about it here today, and some of the biggest newspapers are coming to us and asking us about this for perhaps the first time since we have been campaigning on it—now is the time to put forward bold options in the Green Paper. We think that something like social insurance for people above the age of 40 should be in there. We would be supportive of it. We think that in return for that, the kind of money that could be raised could be spent on more people with dementia and other conditions, who have moderate needs and are currently being ignored by the system, who are falling into worsening states of health; they are being left by the system and are ending up with family carers, who themselves are in a worsening condition. We found that three in five family carers report that their own health is deteriorating because of the volume of care that they have to provide. So in terms of the value for the system, at the moment we are looking at it from the wrong angle.

Q44 **The Chairman:** One thing that is very surprising to me is that about half of the £20 billion or so we spend on social care goes to younger people. Yet all of you have emphasised this idea that, if there were some kind of hypothecated tax, it should be for people over 40. Why is that? That does not seem to be consistent with the pattern of need.

***Dominic Carter:*** That is certainly a challenge. It comes back to intergenerational fairness and the question of who is paying. Part of that system would be about recognising, across society, who is paying into it and who is getting something out of it. That may be a slightly different question. That comes back to the question of fairness and understanding different people's situations, and going from there. As a first, bold step, we can look to international examples.

**The Chairman:** Do you not see that it rather emphasises that social care is a problem for the elderly, whereas the wonderful work you are all doing is focused not just on the elderly but on younger people?

***Kari Gerstheimer:*** Some 49% of people who are in receipt of social care are working-age disabled people, and 30% of that number are people with a learning disability. I think you raise an interesting question.

A mandatory insurance system is usually linked to earnings from employment, but only 5% of people with a learning disability are in employment. Their ability to pay into a mandatory system is really limited. Within any funding solution, there needs to be recognition that there is a need for society to look after vulnerable people who are not able to pay for their own care.

**The Chairman:** I am sorry. I interrupted you. We need to move on to Lord Tugendhat's question, but had you finished?

***Dominic Carter:*** That covers it. My key point was about the unequal system.

***Tracey Loftis:*** To clarify, Versus Arthritis did not propose a certain funding solution. Arthritis affects people of all ages, both under and over 65.

**Lord Tugendhat:** I would like to try to clarify another point. You have each given some quite startling figures about the number of clients—for want of a better word—you have. Do we have any idea of the overlap, or any means of identifying it? A significant proportion of people must come into all three categories: they have learning difficulties, arthritis and Alzheimer's.

***Tracey Loftis:*** Absolutely. On multi-morbidity—people living with many long-term conditions—we are conscious that by age 65, one in two people with a major long-term condition such as diabetes or heart disease will also have arthritis and back pain.

Versus Arthritis and the Alzheimer's Society are members of the Richmond Group, which is exploring the issue of multiple long-term conditions, looking at how we can work collaboratively by bringing in the lived experience and with our information and support offers, and asking whether we can do more to make sure that we are doing our bit for beneficiaries who live with many long-term conditions.

***Dominic Carter:*** Some 90% of people with dementia have another condition. Generally speaking, the older you get, the more conditions you live with. That is particularly true once you are over 90. People are living with very complex differing conditions and that is one of the big demands on the future care system. That is a big demand on the workforce and on funding. It suggests that the social care system is very different from how it was 10 or 20 years ago; we are now asking people working in care homes in the community and in other settings to deliver extremely difficult care, in quite difficult situations.

**Lord Tugendhat:** To what extent do you believe the present means-tested system is fair?

***Kari Gerstheimer:*** We do not think it is fair. It comes as a profound shock to most people that, unlike the NHS, social care is not free at the point of need. We think it penalises disabled people, who see their benefits and assets charged throughout their lifetime. If you look at households living in poverty, 50% have one or more disabled family member in the home. We think the fact that disabled people have to pay for social care throughout their lifetime is pushing more people into poverty.

It is also unfair to older people, who have extremely high care costs. It has a perverse incentive, whereby it discourages people from investing in early intervention and prevention, because they do not want to dig into their savings to pay for it. We support a system which, like the NHS, is free at the point of need.

**Lord Tugendhat:** This is another question to which I think the answer is obvious: how easy do you think people find it to understand? I would have thought they do not find it very easy to understand.

***Kari Gerstheimer:*** It is so confusing. At Mencap, I am responsible for the helpline, the information and advice service and the beneficiary-facing legal team. The people working in the call centre environment are used to working in the social care arena, but they struggle with this. We call our information and advice officers, who have more experience in the system, expert navigators, and they try to help people navigate that extraordinarily complex system. You often come up against it when you are in crisis, so understandably your ability to navigate it is reduced. We have solicitors in our legal team who are social care specialists and they help people understand what their rights are.

**Baroness Harding of Winscombe:** I want to follow up on your passionate argument for a system that is free at the point of need. Is that not roughly what we have in Scotland at the moment, and what do you think of it?

***Kari Gerstheimer:*** Personal care is free at the point of need in Scotland. I come back to my point that it is not right that there is a hierarchy of need. Somebody with a learning disability may not have personal care needs, but they may not be able to get out of their home without support. Without somebody to support them to live a safe and fulfilled life, they may be vulnerable to exploitation or abuse within society. While it is commendable that personal care is free, it needs to be recognised that social care goes far beyond personal care.

**Baroness Harding of Winscombe:** But even in personal care, is it not the reality that it is not really free, but rationed? I am just pushing on whether you see downsides in a free system. In the personal care space in Scotland, do you think this is working for individuals who need personal care?

***Kari Gerstheimer:*** I am sorry. I do not have an in-depth knowledge of how this is working in Scotland, but perhaps someone else on the panel does.

Q45 **Lord Tugendhat:** The Dilnot commission recommended a cap for individuals. What do you think about that?

***Dominic Carter:*** The Alzheimer's Society has quite strong views on the cap, and the cap that is proposed, in terms of recognising the true costs of care. I mentioned before that care for people with dementia often costs 40% more. As has been suggested, the way the cap would be calculated would not recognise those true costs. A cap set anywhere above £80,000 would touch barely more than 5% of people affected by dementia, purely because of how long it would take to reach that cap. Sadly, many people with dementia would not be in receipt of care for that long.

For us, there is a need to recognise those true costs, or to set the cap at a level very close to what Sir Andrew Dilnot suggested in the first place, which was closer to £35,000. However, as with the reflection on free personal care, with the cap, quite a lot of the money involved goes into quite a bureaucratic process and perhaps touches very few people.

We think free personal care reduces social care to very basic means, when a lot of the policy calls—and the wishes not just of politicians but the sector—are about personalisation, understanding people and giving them what they need. But actually so many people are living with complex conditions that we are looking at the wrong end of the spectrum with free personal care.

Instead, we should be looking at what we can do to make sure that people who need that extra bit of help and support, which is costing people hundreds of thousands of pounds and deincentivising care to the point where family carers are worse off. We would like to see a complex care fund, essentially. We call it a dementia fund, which looks at some of the additional needs and costs that people have at the other end of the free personal care spectrum, to make sure that people who need that—

**The Chairman:** Perhaps I am being stupid, but if the costs of care for people with dementia are higher and a cap is set at a lower amount beyond which provision is provided, surely that is beneficial.

***Dominic Carter:*** If set at the right level, exactly so; hence our point that if it is set at £80,000 or higher, we believe it will affect very few people indeed, and at the point at which Sir Andrew Dilnot—

**The Chairman:** What do you think it should be set at?

***Dominic Carter:*** We believe that it should be at an absolute maximum of £60,000; otherwise, it is putting our eggs in a basket whereby—

**The Chairman:** You accept the principle but not the price. Are we arguing about that?

***Dominic Carter:*** Provided that it was put in at the right price, it would be beneficial to many people, but it would still take a long time to come in and we would still prefer to see other systems put in place.

Q46 **Lord Turnbull:** The present system is based on some distinctions. The first is about which conditions are treated by the NHS and which by the care system. Sometimes people might have a medical condition, such as arthritis, but when they go home and have lost mobility it becomes a need for care.

The second distinction is when someone becomes elderly, some adaptations to their home are made, probably paid for by the local authority, and there is an argument about what is social care and what is personal care. Are any of these distinctions useful? If we are trying to devise a new system, do we have to rethink those distinctions and try to base them on something a bit more rational?

***Tracey Loftis:*** At the moment, people with arthritis have told us that trying to navigate all the different health and care systems sometimes feels a bit like being in a pinball machine.

On the point about the distinction, it is very difficult. We have a disease-based system in the NHS that is free at the point of need. We have a needs-based system that is means-tested. The challenge here is how we can get health and social care working towards the same end. Certainly we think that having greater health and social care integration is very helpful. One of the barriers to this is data and having data that flows around the system. Clearly this is something that NHS Digital may aspire to do with the appropriate governance checks in future. However, one of the challenges is navigating the system, so ensuring that people have access to good information is critical.

**Lord Turnbull:** So possibly we need to blow up the rocks so that people do not have to navigate the system. We need to get rid of some of the distinctions and treat this as more of a homogenous system.

***Tracey Loftis:*** I suppose that at the heart of this is identifying a person's needs so that they can be written down in a care and support plan that enables the person to navigate the system with clarity for everyone about their role and the role of different parts of the system.

**Lord Turnbull:** There will be arguments about whether someone comes to you three or four times a day or is a live-in carer. Dressing a wound is nursing care, and the NHS pays for that. Medication is social care and someone else pays for that. It seems to me that there is scope here for endless bureaucratic wrangling.

***Dominic Carter:*** I think we would agree with that. It is quite right to suggest that that comes down to better communication and better working between health and social care.

**Lord Turnbull:** What I think tempts you, and it is quite a dangerous place to be, is that it is all free at the point of need, no matter how much

that costs. At the moment, for adult elderly social care—leave aside working age—I think the figure is £10 billion of public money. You could say, "Well, if that is all free, there is £10 billion the Government will have to pay for". However, against that, the amount of care provided by family and friends is estimated at £50 billion or £100 billion. It is massive. It is many, many times bigger than the care that is actually paid for. If you say that it is all paid for by the Government, which number is it going to be? Is it going to be £10 billion which the Government will pay for, or is it going to be £50 billion?

***Dominic Carter:*** That is a good point. I think the figure for unpaid care contributions is about £139 billion. I guess we would want to see quite a lot of focus on where the evidence lies, where the most effective interventions are for people in need of support and more sensible use of the cash that is out there. Last year, we did a freedom of information request to find that more than 50,000 people with dementia were admitted to hospital with things that could have been completely avoided. On that basis, some of the aspects that you mention, such as a social care requirement or a social care area, which were not acted on perhaps because the eligibility criteria are so strict, led to those people going into hospital where a bed would cost at least £400 a day.

**Lord Turnbull:** We all know in this country that some get there first but not necessarily everyone follows you. Our health service is free at the point of need and completely non-means-tested, so there is no patient/customer contribution. It seems to me that going from a system that has no customer contribution is going to open up such a massive fiscal burden that it will get struck out quite early on. We have to devise something that allows for a customer contribution so that things are not entirely free at the point of need; otherwise, we will end with a system which the Treasury will put a red line through straightaway.

***Kari Gerstheimer:*** There is still a significant part of the population who cannot contribute.

**Lord Turnbull:** I think you were speaking in support of 1% at one stage, but you proceeded to demolish it because you said that half these people cannot even pay 1% as they are not in employment. Also, if it is a national insurance-type thing, admittedly it is it being weakened, but your contribution record has some influence on the benefits that you can get out.

I am not sure that is a principle that we would want to import into how much care you get and say, "How many months of 1% did you pay? You were in only from the age of 40, and you were working for only half the time, so you have a poor contribution record, so you do not get as much care as other persons". I do not think 1% is a great idea. You have to find something else. Also, half the population will have student debt going way past 40. Would we say, "Before you've finished your student debt, you've got to start paying for this next lifetime limit"? This 1% over 40 is a nice, simple idea, but when you look at it I think it crumbles. Have you thought about that?

***Dominic Carter:*** It is the biggest challenge, and the one that our sector keeps wrangling with and consecutive Governments have wrangled with. We say that it would still be a significant step in the right direction, but we need to see more money in that system. As you rightly say, the figure is in the billions. When we look at the cost of the NHS and various other things that the country pays for, it still pales by comparison. We are in a place where we need to be taking those big decisions, because all our charities are finding people on a daily basis who are living quite miserable existences, and at the moment this is largely because of a lack of a support and a point at which people are having to do it themselves.

**Lord Turnbull:** There is a distinction between paying it from taxes and then saying which tax it should be. VAT would be a good tax, or corporation tax, or road fuel duty or whatever. There are all sorts of taxes that you could draw on. Linking it to a tax on employment when all these people by definition will not have good employment records seems rather peculiar.

Q47 **Baroness Harding of Winscombe:** Apologies. I should have declared my interest as the chair of NHS Improvement. Forgive me for not doing that earlier when I intervened.

I want to ask one question, following on from Lord Turnbull's question, about your contention that free at the point of need would be the right answer for delivering health and social care integration. We have free at the point of need in our NHS, but our NHS is far from completely integrated.

In fact, you know as well as I do that different parts of the NHS in different parts of the country do not work brilliantly together. If you park the free at the point of need discussion for the moment, what do you think we need to do to get health and social care working in a better, more integrated way to meet the needs of the vulnerable people you all represent?

***Tracey Loftis:*** It might be good to start with an example. Part of this is about how you get multiple agencies to all have the same shared vision and outcome. In musculoskeletal health, hip fractures are a big issue—there are about 75,000 a year, with hospital costs of about £2 billion[4]. Public Health England has worked with different bodies to have a consensus statement on falls, so everyone is trying to move in the same direction. That is just one example, but with home aids and adaptations, part of it is about understanding what works well, then sharing that. Especially at a local level, a lot of it is about building the relationships and getting people working in the same direction.

***Kari Gerstheimer:*** Ultimately, it needs to start with Government. First, it feels as though we have got off on the wrong foot with the NHS 10- year plan coming out before the Green Paper rather than together with it, then the Budget announcing £20 billion for the NHS but only £650 million for social care. There is also talk of taking people from the social care workforce to prop up the NHS.

[4] Witness clarification: 2 billion a year

Secondly, there needs to be the ability to look across the two sectors and work more closely together. It is also really important to note that, in the same way the NHS is composed of disparate parts, social care is not just about working with local authorities. There are thousands of providers, large and small, across the charitable and commercial sectors. There needs to be integration across the whole sector. That is not happening enough.

Thirdly, in transforming care there is a need to remove some of the challenging, perverse incentives in the system. There is an incentive for local authorities to push people into health-funded placements and a perverse incentive for people not to be discharged from what are extraordinarily expensive support packages, because some of their providers are privately funded. Frankly, they benefit from having people stay with them in a mental health setting.

Having case managers work across social care and health can be really helpful, and it does not happen enough. Some of the success stories we see are where there is one person working across housing, health and social care to try to find a solution for sometimes quite complex problems that need bespoke care packages.

***Dominic Carter:*** I agree that using good examples is the best way to go. There are pockets of really good practice around the country. The Alzheimer's Society provides a navigating service called Dementia Connect. There are other navigating offers out there. One that works particularly well is the Dementia Wellbeing Service in Bristol, which has a dementia navigator that helps people locate different parts of the system where they live. It also brings together GPs, care homes, hospitals and other community providers to understand the needs of different individuals and to put together a personalised well-being plan for people in the area. By doing so, it starts conversations between different services, ensuring that communication lines are opened and that people are known to the system.

One big issue, particularly for people affected by dementia but for many others too, is that if, once they have a diagnosis, it is not a condition that is immediately picked up by the NHS and has an obvious pathway, they often fall out of the health and care system. It is not until they reach crisis point that they are picked back up, and then the costs associated with their care are much higher and their health much lower. To answer a completely different question, for us it is much more about a preventive approach and trying to make sure that people are living lives as well as they can right from the point of diagnosis. The system can work much more coherently and clearly together.

**Lord Darling of Roulanish:** Is it because they are better organised in Bristol that they have brought all this together? If so, what is to stop that good organisation being applied throughout the country?

***Dominic Carter:*** It is a good question. We would certainly like to see that kind of approach picked up and taken elsewhere. This is seen as

being quite pioneering. It is very challenging to get different parts of the sector to work together. I understand it has taken a lot of hard work to do so. Part of the reason for mentioning it here is to try to promote that.

**Lord Darling of Roulanish:** It sounds like a good thing, and people have talked about this for a long time. I do not understand why, if it can work in Bristol, it cannot work in Birmingham or anywhere else.

***Dominic Carter:*** I would like to agree, and I certainly hope so. So many of the systems and localities work so differently that it involves 101 different people to come together. People with dementia often come across 20-odd different professional groups that are involved in their support. If those groups are different, it can be very difficult.

**Lord Darling of Roulanish:** It might be useful for us to consider how much of this is organisational, as opposed to money-related.

***Dominic Carter:*** Yes, and I think you can see progress if you locate pockets of money for areas that are willing and keen to focus.

Q48 **The Chairman:** Perhaps I could ask the next question, and the challenge is to answer it without using the B-word. Do you agree with the Migration Advisory Committee that the sector's problem is its failure to find a funding policy that allows the payment of higher wages? Were you concerned by the dismissal of an explicit work migration route for low-skilled workers in its recent report? It is an easy question.

***Kari Gerstheimer:*** We are very concerned by the estimates of shortages of 500,000 care staff by 2030. Our position is, first, that the phrase "low-skilled worker" should not be used in relation to care staff. We think that that perception needs to be challenged. There needs to be a greater emphasis on professional structures, career development and appropriate reward. Of course, we would urge caution in relation to any Government policy in the current context of there already being recruitment and retention problems in the sector. There are big problems with recruitment and retention. As a provider and an employer of care staff, we have been doing a lot of work on valuing the workforce and trying to create a more professionalised structure. We are trying very hard to be a national living wage provider; that is our policy. But as a care provider we are competing against supermarkets and retailers paying higher wages that we simply cannot compete with. Those workforce challenges are really critical to the system.

I come back to the sleep-ins crisis and the £400 million back pay. You will be aware of a case that may well go to the Supreme Court in the new year. It really threatens our ability to pay staff appropriately. Some local authorities have already said that they will go back to paying a sleep-in shift rate rather than the national living wage for a sleep-in shift.

**The Chairman:** I know from personal family experience—I entirely agree with your point about low skills—that what is extraordinary is the dedication and commitment, and how very poorly paid those people are. They are not doing it for the money, and these are difficult jobs. How do

you see that being squared? Those people provide care outside the family, but we also have unpaid carers within the family. What can be done to provide additional support to them?

***Dominic Carter:*** When we looked at the amount of unpaid care available for people affected by dementia we looked to about 2035. There are great concerns about whether there will be enough unpaid care left at that point for the number of people living with the condition. If there is not you will be reliant on the professional workforce, which has a significant shortfall already that is likely to grow. What do we do then? Do we leave them to fend for themselves? This needs to be addressed and clarified as soon as possible.

On wages, we are clearly expecting people to support those with extremely complex needs and conditions, such as dementia and some of the conditions that the panel supports. On that basis, we have seen what would have been the role of a district nurse, with the terms and conditions afforded to staff in the NHS, fall on roles where people are given very little training and support to none whatsoever. We did an investigation back in 2016 which found that one in three homecare workers had no dementia training whatsoever. I would not back myself to go into somebody's home by myself to provide care to someone with advanced dementia. I would want that help, supervision, advice and confidence to do a good job. The vast majority of care workers want to do a good job. As you said, they do not get paid appropriately. They are doing it from the goodness of their heart, but how long can we expect that to continue?

**The Chairman:** Also, they do not really have a proper career structure, training and infrastructure.

***Dominic Carter:*** That is right. Similar to the situation with the Green Paper and long-term planning coming out separately, we are seeing suggestions that there will be workforce strategies for two different sides of the coin, whereas we should be looking at how we can increase investment and support for that social care workforce, where so much of the demand will increase as time goes on.

**Lord Turnbull:** Ms Gerstheimer, I think you used a phrase about the NHS drawing on the resources of the care sector. In a sense it is a double whammy. Under certain immigration policies, the care sector will find it more difficult to recruit the kinds of people it needs. Secondly, if you are an NHS manager the easiest way to boost your number of staff is to go to the part-trained staff in the care sector. I suspect that that is where these labour market and recruitment problems will be focused. There be quite a big hit there.

***Kari Gerstheimer:*** We would absolutely agree with that analysis. It is a big risk.

***Tracey Loftis:*** In terms of informal care we know that We know that there are about 5.4 million informal carers in England. We also know in terms of trend data that from 2001 – 2011 that increased by 11%. Clearly, people are already doing a huge amount for their loved ones. We would agree with much that has been said already about unpaid carers: this is a very valuable role, helping people with a lot of the basics in life that help to maintain a person's dignity, such as going to the bathroom. The Migration Advisory Committee is currently consulting on what roles should be part of the Home Office's shortage occupation list, so there is an opportunity to discuss which

social care roles should be added, especially given the short-term pressures on the system.

Q49 **Lord Darling of Roulanish:** May I ask another general question? Could you give us an example of where we might usefully look at where other countries are doing it better than we are? I am thinking particularly about care for working-age people, because too often when we look at care, people tend to think immediately of what happens to 80 and 90 year-olds. Could you point us to areas of the world where you think countries are doing it better—or even to a perfect example?

***Kari Gerstheimer:*** In Australia, working-age disabled people do not have to contribute towards the cost of care. It is certainly worth looking at that system.

**Lord Darling of Roulanish:** Does that include someone who might have absolutely nothing to worry about until 35, and who then has an accident or something else happens, and they recover to a greater or lesser extent? Is the care that people need free just at a point of crisis, or are you talking about people with such conditions way before they would be working—in childhood and so on?

***Kari Gerstheimer:*** My understanding is that it is all working-age disabled people, but I am not an expert in the Australian system, I am afraid. There are some quite interesting models domestically. Leonard Cheshire has been trialling an interesting model whereby it has pooled personal budget holders to commission their own care. That empowerment model is quite interesting.

**Lord Darling of Roulanish:** That is domestic?

***Kari Gerstheimer:*** Yes. Investment in the short term can often yield efficiencies in the longer term. Looking at the Transforming Care issue again, people are in receipt of very expensive packages of support in mental health settings, with investment in the workforce to deliver very specialised care over the long term. There is the ability to save money, because people can have a reduced level of support over the longer term if they are receiving specialised support in the community.

**Lord Darling of Roulanish:** But apart from Australia, you would not refer us to anywhere in particular.

***Kari Gerstheimer:*** When it comes to working-age disabled people, I could not comment, but I know that the Health Foundation has done some interesting research, with which you will be familiar, which considers different funding models.

**Lord Darling of Roulanish:** What about you, Mr Carter?

***Dominic Carter:*** When we have looked at international examples, those that tend to be mentioned are Japan and Germany. The interesting element of them is that it is not just the individuals who are paying in: employers are contributing.

**Lord Darling of Roulanish:** Going back to Lord Turnbull's point, both those countries have a history of co-funding, whereas our history is that it is either free in the NHS or not free at all.

***Dominic Carter:*** Certainly, which is clearly a significant challenge and it is probably about having admittedly challenging conversations about that and looking at the benefits for employers, for example.

**Lord Darling of Roulanish:** I have the impression from all three of you that, when pushed, you came to the free at the point of use argument rather than co-funding.

***Kari Gerstheimer:*** Any solution needs to be culturally appropriate, and given that we already know that a significant proportion of the population already thinks that social care is free at the point of need, it appears that that is a culturally appropriate system that we are used to with the NHS.

**Lord Darling of Roulanish:** It is, but someone can say, at one and the same time, "I think it ought to be free", and "No, I don't want to pay any more tax". That is not an unheard-of phenomenon.

***Dominic Carter:*** At the moment dementia care can cost up to half a million pounds. That is an unbelievable amount of money that leaves lots of people with nothing left whatever. We want something introduced—we know it will be a big challenge—which takes away some of that burden and takes us in the direction of free care at the point of use.

It may well be that that is a longer term ambition, but the conversations that we are having now and the momentum behind this cause could get us to a point where people are not paying catastrophic amounts but can access care if they have mild or moderate needs. We want to ensure that the combination is there and work towards a point where care can be free at the point of use as an ambition which, to be honest, society should be favouring and would help a lot of people.

**Lord Darling of Roulanish:** Although it has escaped us for the last 25 years.

***Tracey Loftis:*** To add to colleagues' points, I am conscious that 30.8 million working days are lost because of a musculoskeletal condition, so clearly this is a big issue in the workforce. Because of social care pressures, we have seen more care targeted at those with severe needs. What is important, especially for the working-age population, as we know from Carol Black's work, is that good-quality work can really help people. Therefore, helping people with moderate needs to remain in work and taking a preventive approach so that they are not living with severe

needs is crucial, especially with the Government's current work on helping disability.

**The Chairman:** You have not really tackled the problem that worries me—this will sound rather brutal. The amount spent on social care is roughly £20 billion—it is of that order. That is a very small number relative to the amount spent on the health service, but if you cost the amount done by families, that is a huge number. If we had a magic money tree and said that we would make it free, my anxiety would be that with a lot of the care being provided voluntarily by families, sometimes with considerable difficulty and distress, people would say, "The state can do that now". Therefore, the amount of resource that would be required to fill the gap would grow exponentially.

Is that not a worry? I understand the point you are making about it being free and you have a system that spreads the risk across the community as a whole, but there is this dead-weight cost—a rather crude way of putting it—of the care provided by families, which might not then be there. What is your response to that?

***Dominic Carter:*** For us, it is about making it a step change and looking at what we can do in the short and medium term, working towards the point where there is free care at the point of access.

**The Chairman:** That does not address the point. That is saying, "We need more money, and we do not really mind what the policy is as long as we get more money".

***Dominic Carter:*** You asked what would happen if all care was free. We are particularly concerned that complex care is not only not free but is charged at additional sums. Can we support families and individuals by providing more complex care, which we believe to be a bit of an oversight and blind spot for the NHS, which it is actually very convenient that social care picks up—the very complex aspects of care for someone affected by dementia and many other conditions?

If we can look at that first and support families with the highest concentration of hours, stress and concern and move from there to a point where we start to think that the public are more engaged with what this covers, we can expand from that point. That is the Alzheimer's Society's push. We are losing people by failing to acknowledge complex issues.

***Tracey Loftis:*** Carers already do a huge amount through love and a sense of duty and responsibility, but I am conscious that there remains unmet need. A lady we spoke to, Anna, from Stockport, who is in her 50s, is living with osteoporosis and fibromyalgia. Her granddaughter is her main carer. She has some support from her local authority, but when her granddaughter is not about she has to crawl on the floor to get to the toilet. Part of what we are trying to do is ensure that we have a system providing good-quality care across the piece.

**The Chairman:** Thank you very much. It has been a really interesting session and I am sure that the whole Committee would want to thank you for everything that you do in this area as a charity. We are very conscious of the stress and strain in the system and will try to produce a report which adds something new to what has been a very long-standing debate and, we hope, enables us to make some progress.