

# The Joint APPG Inquiry into Social Care Reform for Working Age Disabled People

19 March 2013

## The Value of Preventative Care

### **Members:**

*Heather Wheeler MP (Chair)*

*Baroness Eaton*

*David Ward MP*

*Baroness Uddin*

*Charles Walker MP*

*Baroness Wilkins*

### **Witnesses:**

*Sarah Pickup, President, Association of Directors of Adult Social Services*

*Councillor Lynn Travis, Local Government Association*

*Sarah Lambert, Head of Policy, National Autistic Society*

### **Heather Wheeler MP**

It is almost one o'clock, so I think it would be absolutely excellent if we could start. I hope not to detain you longer than an hour. Thank you so much for coming along. I think it would be quite good if we went around the table and introduced ourselves. Some of us have met before. I am Heather Wheeler. I am Member of Parliament for South Derbyshire. I am Chairman of the All Party Parliamentary Local Government Group, which is why I have ended up doing this joint inquiry with the All Party Parliamentary Group for Disability as well. So that is me.

### **Baroness Eaton**

I am Margaret Eaton, and I am on the Conservative benches in the House of Lords. I have a background in local government.

### **Charles Walker MP**

Conservative MP for Broxbourne.

### **Baroness Wilkins**

Rosalie Wilkins, Labour peer with a background in disability issues.

**Lynn Travis**

I am Councillor Lynn Travis, for Waterloo Ward in Tameside. I am a Labour member and lead member for adult services, health and wellbeing.

**Sarah Pickup**

I am Sarah Pickup. I am President of the Association of Directors of Adult Social Services and Director of Health and Community Services in Hertfordshire.

**Sarah Lambert**

I am Sarah Lambert, and I am Head of Policy at the National Autistic Society.

**Heather Wheeler MP**

Lovely. Thank you very much indeed. Some of our other colleagues will be joining us. So if I may, perhaps I could kick off with a classic question. Perhaps each of you would like to describe how your organisation defines preventative care.

**Sarah Pickup**

A lot of the time when we talk about preventative care, we tend to be talking about older people or people with long-term conditions which can be prevented. There is a tendency to think you can prevent a condition arising, you can prevent it getting worse or you can prevent a hospital admission. At ADASS we do not have a definition, but when we talk about preventative care, I think what we need to talk about is much wider than that. It is about preventing escalation: preventing the need for more acute or higher levels of care that could be avoided by earlier support or intervention. That latter point is very important in relation to working age adults. So you may not be able to prevent a learning disability or autism, or even a mental health problem. But actually, there are some things you can do to prevent escalation, and some things you can do to get better outcomes, and I think that is where we see prevention in a broader context.

**Heather Wheeler MP**

That is very precise and concise, thank you very much indeed. Perhaps if I could now ask you, Sarah Lambert, to give your version.

**Sarah Lambert**

Sure. I would very much echo many of Sarah's comments. We were pleased to be invited to this session, because when we talk about preventative services it is the older age and preventing the development of diseases. However, for people with autism, who typically struggle with social interaction and social communication, the things that might prevent them from developing further needs are things like social skills training and befriending. There is a whole range of low-intensity support that can be put in place at an early stage to prevent that group of people from developing further mental health problems, from being socially isolated and vulnerable to exploitation, and perhaps inadvertently entering the criminal justice system if they are vulnerable to exploitation. It

is about the range of different services that can be put in place to prevent people from developing additional problems and additional needs.

**Lynn Travis**

I think from a local authority viewpoint, it is much the same. It is about promoting and supporting wellbeing and enabling people to live fulfilling lives in the way that they wish to. It is also about offering access to universal services, and also to specialist services, as required. That is the general way for all local authorities. It is about early intervention and identifying people's needs, and also being able to identify any risk of change or deterioration in people's conditions that may lead to more intensive care. It also focuses on reducing the need for more complex health and social care needs.

**Heather Wheeler MP**

Very helpful, thank you very much indeed.

**Baroness Eaton**

It was most interesting to hear what you have said about your descriptions. In the climate we are in, do you think that preventative measures are simply used to prevent spiralling costs in care, or are they used for the reasons you describe?

**Lynn Travis**

I think it is a combination. Obviously, in the climate we are in, we have to look at cost-effectiveness. But it is not about savings; it is about making sure that the right kind of care is targeted at the right people at the right time. There are ballpark figures for monetary savings about. For every pound spent in local government, the fruit falling in other gardens such as the NHS saves about £1.40 and upwards in healthcare needs. So there is a benefit in financial terms, but the real benefit is in community terms. I think this has already been alluded to: the prevention of isolation, the prevention of unacceptable behaviour, which occurs because people are not getting the kinds of services and care that they need, and the prevention of minor crime, or even major crime in some instances. Not everybody is the same. It is not a one size fits all. Everybody has different needs at different stages of their life. So no, it is not just about cost saving, although we do have financial benefits.

**Baroness Eaton**

Does anyone else want to add anything to that particular comment?

**Sarah Pickup**

I would just like to add that prevention is one of the very few things where you can get both a better outcome and a reduced cost.

**Baroness Eaton**

So it is both.

**Sarah Pickup**

We are absolutely beholden to prevent things are preventable, and we do not do it as much as we should.

**Baroness Eaton**

I know it is not one of the things I was supposed to ask about, but –

**Heather Wheeler MP**

You are on a roll, Margaret, you are on a roll.

**Baroness Eaton**

You talked about the fruit falling elsewhere. Do you think that more flexibility around budgets regarding different services would help? There is a very small example – one I have always quoted – where a hard-pressed local authority with very limited cash might be having to limit winter gritting. Yet if the Health Service could contribute towards winter gritting on pavements near elderly complexes, it would save them a huge amount in fractures. Those kinds of things do not happen. That is prevention, is it not? But those kinds of things do not happen. Would it help if there was more of that kind of flexibility on those small things?

**Lynn Travis**

Absolutely. To be fair, there has been a growing movement for many years towards integrated services of that kind; towards looking at how each of our partners benefits the others in the way that we work. This has picked up much more speed recently, with a lot more intensive work done about real integration of community budgets. It varies such a lot across local authorities, but certainly at Tameside it is something that we have actively pursued, looking at how we can make the best use of the benefits that each of our partners brings to the table.

**Baroness Eaton**

And flag up the community budgets.

**Heather Wheeler MP**

Does the National Autistic Society have any examples of where you do this kind of joint working?

**Sarah Lambert**

One of the clearest areas has been the development of local autism teams. There is one in Liverpool, for example, and another one in Bristol. They are supported and funded by both health

and social care. The National Audit Office did some modelling on the Liverpool Asperger Team in particular. Most local authorities do not know how many people there are with autism in their area. What the Liverpool Team do very well is identify people with Asperger syndrome and then look at developing and supporting them, providing them with a lot of these low-level types of support that we have been talking about today.

What the National Audit Office found was that if local services identified and supported just 4% of adults with high-functioning autism or Asperger syndrome, the outlay would become cost neutral over time, and if they identified double that, 8% of adults in their local population with Asperger syndrome, then the Government could save £67 million a year. If you look at that in a bit more detail, the cost tends to actually fall on the NHS in terms of identifying and diagnosing adults with Asperger syndrome. The delivery of the services is saved to local authorities because they have been identified and are able to get better support. The National Audit Office found that for an 8% identification rate, the cost to the NHS would be about £30 million, but the savings to the local authority would be about £100 million. So there are significant savings to be made when health and social care services come together and work the pathway through for people with autism. I am sure that is the same for other disabilities, too.

### **Heather Wheeler MP**

Thank you very much.

### **Baroness Wilkins**

What steps could the Government take in the Care and Support Bill to promote preventative care services which empower working age disabled people to contribute to society?

### **Sarah Pickup**

In the Care and Support Bill, there is a duty for local authorities to promote prevention. Again, a lot of people have seen that as the older people's agenda, around prevention. But if you read the words of the Bill, there is nothing that says they do not apply to working age adults. Indeed there is a lot in the Bill; and if you take the Dilnot proposals, which provide free care and support to people who turn 18 with an eligible need alongside it, then you have got a set of measures which are addressing the needs of people of working age.

I do think you have to think about prevention in a quite different way. The personalisation agenda is very important for working age adults in terms of prevention. We were actually talking outside and thinking about the Winterbourne View scandal, and the kind of people that are in those independent hospitals. What you end up with is a vicious circle of challenging behaviour, because people are living in places they do not like living in, with people that they have not chosen to look after them, and without enough to do. Their behaviour remains challenging because they do not like being there, and they find it hard to communicate that.

If you can move them to an environment where they are living somewhere they like living, and doing things they like doing supported by people that they like, then you can actually prevent that escalation of needs, you can prevent the need for an independent hospital placement, and you can help people, again, to have better outcomes at lower cost. Where we have been able to do those things, what we have found is you move people, it takes a lot of effort – so do not skimp on the

assessment and care management bit of this, because actually, putting it in place is really important. So making sure that we do not pretend that that is not a valid cost is important for the Bill – particularly for complex cases. So do not skimp on that.

When you put it in place, it still costs a lot, because these are people with high needs. But actually, sometimes it costs less as time goes on. For example, you do not need the waking night care anymore, because there cease to be issues at night, because people are comfortable living where they live, and so on. Of course it is not the same for everybody, but in terms of the Bill there is a focus on personalisation; there is a duty around prevention. For a lot of people of working age, the personalisation, in and of itself, if done properly, is preventative in terms of escalation. Think about things like mental health, access to early, practical support and talking therapies rather than waiting for the crisis.

### **Sarah Lambert**

Thinking about the challenging end of autism – people with more complex and challenging behaviour – there is a need to think earlier, about school and how that works. We were talking about a guy who ended up in one of our schools. We run seven schools across the UK for people with autism with the most complex behaviour. This guy had been failed by so many other schools, but through being given the right support in school by us, he went on to do a master's degree in engineering. So he clearly was very capable, but had been failed so much at an early stage that he had developed much more complex needs and needed that quite expensive and complex support.

In terms of the Bill itself, one of the things that we have been looking at around Clause 7 is whether there is a way to put something within that clause that can indicate to local authorities where they can find best practice. For example, NICE have developed some guidelines on managing autism in adults which indicates some of the clear preventative measures that you can take to better support adults with autism. There could be a way through the Bill to indicate to local authorities that this is where they can find out about where best practice is, where they can see regulations or guidance. It is just about trying to show local authorities where the evidence is and giving them guidance about what does work.

### **Lynn Travis**

That will be crucial. The Bill gives a broad direction of travel that is quite positive, but there are some gaps, which I think have been alluded to. It is unclear whether the nought-pounds cap still continues after the age of 40, for instance.

There are other things. We have already spoken about how local government and local authority budgets are going to be cut, and the biggest spending area is social care. Whilst we celebrate the fact that people are living longer, it does put additional pressures on to local government. All these things need to be taken in to consideration. We talk about personalisation and prevention and that is fine, but we really need to be able to fund all that. We need to have sufficient funding and sufficient room to be able to give that personal care, to be able to direct people into living the lives they aspire to.

The Dilnot model was quite good, but it still has not been embraced by the new legislation that has been put forward. We also have not talked about eligibility. Many local authorities are really cranking up their eligibility and probably only looking at the very worst cases. If we actually want to have a proper agenda on prevention and personalisation, we really need to be looking at early

care: earlier than when it becomes a crisis. In that way, we are only fire-fighting; we are not actually dealing with the issues.

### **Sarah Lambert**

That has been a massive challenge over the last few years. As local authorities really tighten their eligibility to critical and substantial, they can only be a service of last resort. Working out how to move that money down, without failing those people who are critical and substantial, is a real challenge. As the NAO showed, though, it can actually be cost saving in long run, as long as we get it right.

### **Baroness Williams**

Are there gaps that you would identify in the Bill?

### **Sarah Pickup**

I am not sure that there are gaps, because I think that what really comes out of it will transpire when the regulations and the guidance are set. The Bill provides a good framework and I think it provides scope for doing most of the things that we would need to do, but a lot of it will depend on what is written in the regulations and the guidance underneath, and that will be important. For example, the prevention duty: it is a very general duty. So what will that mean, what will we have to do? Will it encompass working age adults?

I think eligibility is an important factor, but what we must remember is that it is not the case that the only things we do are for people with eligible needs. Eligibility is really about your eligibility for ongoing support. There are a lot of people who we provide preventative care or early intervention to so that they do not need ongoing support; and they do not always have to be eligible in order for us to do that. Certainly in Hertfordshire, we have a whole community infrastructure, largely through the voluntary sector, but also through things like housing-related support, and we are about to implement telecare on a preventative basis for people who are, as it were, pre our eligibility threshold.

And all of that is about preventing people escalating to that higher level of need, which again gives you the better outcomes and the lower cost. So it is not the case that all we do, and all we are allowed to do, is for people above eligibility. But there is, of course, a big funding question which is about the challenge of ever-increasing financial pressures. The bigger financial pressures are probably around learning disability rather than older people. I am not saying that older people is not a demand, but the bigger financial pressures are probably for people with disabilities, actually. You can meet the higher level needs in the most effective way you can, but it does make it hard to shift funding back downstream – which is where you really need it.

### **Sarah Lambert**

The other thing the Bill could be a bit clearer on is advocacy. I do not think there is a clear enough duty on advocacy. It is something that we have found that people with autism in particular are not getting, but would like to get.

**Charles Walker MP**

One of the big issues at the moment is the relationship between continuing care and the NHS, and social care and the NHS. Do you think there are sufficient measures to ensure that less strain is put on the NHS and other related services by earlier interventions on the behalf of the people that you work with?

**Lynn Travis**

I think you have probably answered that, in a way, in your question – continuing healthcare. This goes back to what I was saying about having a properly integrated service across a person's life course, so that local authorities can be working with their health partners to ensure that the right care is provided to people at the right time. Continuing healthcare, which is really for when people are at a very vulnerable stage in their lives and need much more intensive care, is something that has always been, in some areas, a bit of a bone of contention. But it has always been something that the local health service – PCTs, usually – and local authorities have had to work out together, with varying degrees of success.

I am trying to speak broadly on behalf of a lot of local authorities. I know our authority has worked very closely, but there has always been that division of funding. For example, we pay for the care in the home, but any nursing care is paid for by the health service. What we really want to be working towards is that it is seamless, and that it is one cost as people move through, and need that level of care. And that is where there are quite a lot of integration pilots. And I know that in Tameside we are working with Ernst & Young on integration. We have already looked at integration for people with dementia, and we are now working on integrating our services and the budgets, where possible, for the whole of our adult social care. But it is very variable across the country: different authorities have different approaches to that. Would you agree?

**Sarah Pickup**

Yes. I think that the evidence from some of the trials and early implementations around the country is that it is probable that if you spent more money on social care – the right social care, not just any social care, but preventative social care – you could spend less money and prevent admissions to hospital. Torbay is much quoted, sometimes to everyone's annoyance. But the outcome there is that actually, they are spending health money on social care, because by spending more money on social care they have been able to prevent hospital admissions.

In Hertfordshire, we have some trials going on – I think there is one going on in Charles' area, or nearby – which are called 'Home First'. They are conducted by a joint social care and healthcare team. It is about picking up the people with long-term conditions at risk of moving on. They could be of working age or they could be older people. It will be a bit of a mix of both. The assumption that we are all working on – and the evidence so far suggests it is correct – is that we will have to spend more on social care. But the health service is recognising that and saying, 'We recognise that if the impact of this is that we have to spend more on social care, we will pay, because it is worth our while spending that to prevent the acute beds.'

**Charles Walker MP**

Have they got the flexibility in their budgets to do that? Obviously there might be an upfront cost before you see the benefit. It is called dynamic modelling and the Treasury do not do it, as I know you know. So how can they find the capacity in their budget to do the sort of front legwork?

**Sarah Pickup**

So PCTs and CCGs have had, in the last couple of years, to set aside a proportion of their budget for transformation, and that is the money they are using to pump-prime some of these things. To be fair, we are spending some money too. We have some government grants around things like winter pressures, so we put a share of our resources in to try things out and make sure they work. But what you have to do is make it work in the system. If a CCG finds something that works, they have then got to decommission something else. The proof will be as we move through the system.

Someone asked earlier about whether we have enough flexibility. The flexibility is all there, but it is really about, 'Why have we not done some of these things so far?' People can spend money on winter gritting if they want to, and they can spend money on social care if they want to. But it is actually about the perverse incentives in the system, and the drivers being different drivers historically – but the drivers are shifting. Now that a focus on integration, and the duties on different players to play their part in that, has been built into all the recent legislation – guidance, bill, white paper – I think we will move forward more readily than we have done previously.

**Heather Wheeler MP**

Sarah, do you have any thoughts on that part of it?

**Sarah Lambert**

In terms of autism services, the Government is going to be reviewing the implementation of the Adult Autism Strategy this year, and we have been doing some research – talking to professionals around the country about how they feel the implementation is going. Admittedly, we did talk to more local authority professionals than to health. One of the key findings of that is that they were having some difficulty engaging with health and getting them on side. Part of that is because the strategy has been seen as quite social care-led, and a lot of the health people have not necessarily seen it to be as much their responsibility as they should do. The other thing is that we are obviously going through a massive restructuring of the NHS at the moment, so I think minds have been concentrated elsewhere. We will certainly be trying to push that; as the review of the Adult Autism Strategy goes forward this year, we will be trying to up the profile of the need for health to engage with local authorities on this issue.

**Charles Walker MP**

Just slightly off the plate, how much undiagnosed Asperger's – perhaps it is difficult to know because it is undiagnosed – and related conditions do you think is out there? There was a piece in the newspaper yesterday about it.

**Sarah Lambert**

Asperger syndrome and autism are massively underdiagnosed, particularly in older adults. In children's services, awareness has improved, and as a result, people are being identified much earlier. But the current problem is that there is a big group of people who are not diagnosed at the moment.

**Charles Walker MP**

And there is a potential cost attached to that diagnosis, is there?

**Sarah Lambert**

A potential cost, yes. The National Audit Office's report was really looking at, if you do not identify that group of people – particularly the people with Asperger syndrome and high-functioning autism who will be out in the community – and put the right support in place, then actually they are prone to a lot more social isolation. They could work, potentially, but you would not necessarily know what types of support could help them into work. So that failure to identify them has costs in terms of welfare, but also costs related to the development of severe mental health problems.

We did research a couple of years ago where two thirds of adults with autism told us that they were not getting enough support to meet their needs. A third told us that as a result, they had developed severe mental health problems. We have statistics that said these people were experiencing anxiety or mild depression, but it was a third that said they were experiencing severe mental health problems as a result of the lack of support. Without identifying that group, it is impossible to put the right support in place to prevent some of those additional problems from developing.

**Baroness Eaton**

Mine is a slightly technical point. It is going back to what you said about flexibility between the different budgets. Maybe it is because I have misunderstood, so perhaps you can clarify for me. I was on the Committee that looked into the draft Care and Support Bill. There was quite a big discussion around previous Health Acts which really clearly defined what could be spent on health and what was not eligible. Has that been lost, or is that just about residential care? It was a long discussion that we had about it. It would mean that you would be not be able to be that flexible.

**Sarah Pickup**

Where you have the will, there is usually a way of doing it. I think that technically, the local authority cannot spend money on health services that should be owned by the NHS. But if you pool budgets, then you can actually make flexible use of resources.

**Baroness Eaton**

Right, that is the answer, thank you.

**Sarah Pickup**

The health service cannot do direct payments, but if you pool budgets – so there are some ways and means of doing things where there is the will to do them.

**Baroness Eaton**

Thank you.

**Heather Wheeler MP**

I think councils are as innovative as they want to be.

**Sarah Pickup**

There are grey areas, too. In order to get the independent sector to build a new facility in Herfordshire, which replaced a hospital but which was on local authority land, we agreed to fund the intermediate care beds if health funded the therapy. But it is a pooled budget, and technically, that is health spend. But at the end of the day, we all got a better deal, as did the citizens, as a result of working together. It was quite complicated at the time.

**Charles Walker MP**

Local authorities are much more innovative at these sort of things than central Government. Central Government lectures local government on what it should be doing, when actually local government is well ahead of central Government in most areas. One of the most important at the moment is reducing costs, but actually, while they are reducing costs, being much more innovative in what they do.

**Baroness Wilkins**

Agree.

**Heather Wheeler MP**

We have been joined by our Liberal Democrat colleague, David Ward. Pleasure to have you here David, thank you very much for joining us. I will tease one more question out and then, David, perhaps we might get to question seven, if that is all right with you. I think we possibly touched on this already, but I am wondering whether each of you could give another couple of examples where you can demonstrate where the investment in preventative care has reduced demand on the NHS and crisis care support, and actually housing as well. I wonder if any of you have got any examples on that.

**Lynn Travis**

As Charles Walker has just said, there are so many innovative schemes across the country, particularly around housing and social care housing – housing that promotes independent living. For instance, in Tameside we are currently trying to bring people out of unsuitable housing. We do not have anybody in institutional care anymore, but we have young people who are in homes or places not as suitable, so we are working with Creative Support and other providers of properties, to have purpose-built properly arranged accommodation, so that it is accessible, but also promotes their independent living.

I think that is really important to take people out of multiple care settings and multiple housing, and to promote their own independence, with support maybe from telecare or some kind of warden visit on occasion. This is a whole different level of support, depending on who is living there. But I think it is about promoting independent living.

One thing that has not been touched on is that there are sometimes issues and difficulties around the transition into adult services. When young people are identified with learning disabilities, they are in the care of children's services until the age of 16, but at that transition into adult services, there is quite often a substantial reduction in the levels of care and support, and this was the case even when times were not as difficult financially as they are now.

The transition has proved difficult in cases, and that is an important area that local government has to look at, and something that perhaps could be looked at in terms of any government provision because that is where there is a potential gap in the kind of service levels that people can reach. I think the main thing is about promotion.

I have other authorities that are still working on this. At Southampton, they have changed the day services, so that people were not so reliant on building provision, because that is another area where people tend to go to the day service centre. Southampton, along with ourselves, are trying all kinds of activities and day services that people can access themselves – according to their choices, not a set programme. There will be some set programmes, but generally, if they want to go to cinema club, or they want to take part in dance activities or different things, it is about us bringing in those kinds of opportunities. They are often provided by voluntary groups, community groups, or small social enterprises. These organisations can provide these much-needed services when the local authority can no longer just say 'Here's the money' or when they have previously been providing them in a building setting.

I have wandered around a bit, but I was trying to bring that in. It is about how we can offer the opportunities and choice, through personalisation, that people need.

**Sarah Pickup**

I have a general point and a couple of unusual examples, I suppose. The general point is that many of the services that we offer prevent cost to the NHS. So for example, we have, for the first time, been able to join up care and health data; we can profile an individual's episodes of care. I was thinking about a particular individual, whose profile I saw. They were in and out of A&E, and then they were referred to social services, because you could see they were getting home care. And the A&E admissions tail off. It is not that they never go to hospital, but they were in a revolving door

situation, and then they obviously had a social care assessment, and got some more regular support. Even some of our core traditional services can be preventative, then.

Thinking slightly differently, alcohol is one of the reasons people end up in hospital. Alcohol harm reduction can prevent cost to the NHS. Some of the things we do to prevent crime, like putting taxi marshals in town centres on Friday and Saturday nights, not only prevent crimes, but they also prevent hospital admissions. Usually, that is a partnership between the police and the local authority. You are preventing a cost to the health service and actually having a dual impact for something you do. So it is all about looking at what we can do together.

Other examples I would give might be around falls prevention. In Hertfordshire, the fire service do smoke alarm checks, but while they are there, they also do checks for falls hazards and they give advice about the dangers of smoking. If the police are out on work related to distraction burglary and they fit a camera, that can be helpful for knowing if someone is moving around the house if they are a vulnerable adult. It is a bit like the 'Every contact counts' thing in the NHS. What we need to do is use all our services to support people in our communities, and those things will save the health service money. Some of it is about social care; home care. Telecare and telehealth are really good examples. If you monitor someone's vital signs from home, they do not always need to go to the surgery, or somewhere else, for their treatment.

I will mention some of those more unusual things: supporting carers well, so that they can cope; putting support into care homes and supported living settings, so people can die in those settings and avoid going into hospital. Some of that is about us training our staff well. Some of it is about the community health services providing good support into those settings. So it is all sorts of things; and it really is that mix of things. You can see the evidence for those things in many places. It is not nebulous at all.

### **Sarah Lambert**

I would go back and emphasise the importance of local autism teams. Across the country, these are increasing in number, and where they are working well, it has been as a result of local authorities and health coming together. There is a real under-identification, as we touched on briefly, of autism. Very few local authorities and health services will know how many people there are with autism in their area, and so they are not developing the appropriate services as a result. These types of team can be really important in terms of identifying those groups and then supporting other services in the area to actually support people with autism better. So developing these teams is not about creating a whole new area. The concern quite often when we talk about the development of local autism teams is that they will suddenly have a huge caseload of everybody with autism in the area. What the National Audit Office report showed is that it is about getting these teams in place to identify people and work out what their needs are, and then looking to meet those needs.

I also mentioned just now about how we have been doing some research on how different areas are doing in terms of implementing the adult autism strategy, and one of the professionals that we spoke to in Kirklees talked a lot about the community groups that he has been developing in his area. There is a range of different types of community groups and there are four autism support groups. His description of the service was that there has been real political will in Kirklees to say 'This is going to work. We invest early on and will prevent more crisis services later on.' They believe that the investment in these community groups has led to around a 20% reduction in community care referrals. It does not cost very much at all. I think they charge the people that go

along to the autism group £1 a time to cover coffee, or whatever else. So they are really low cost services, but they are seeing massive reduction in the referrals as a result.

**Heather Wheeler MP**

Absolutely excellent – thank you very much.

**Lynn Travis**

Could I just add something that has occurred to me, as well? I touched on education, and particularly how many people with learning disabilities or autism cannot access education. On Tameside we have been providing education services for people with learning disabilities, and unfortunately much of that has had to be cut back. Following on from that, because we are talking about working age adults, we have had projects about routes to work. A lot of local authorities have had similar projects which have been to give people additional support, to help them gain employment where possible.

These, unfortunately, are other areas that are having to be cut back. They are areas that need to be substantially funded, and give people who receive that kind of training and opportunity a real sense of potential and aspiration to take part in society. I find that that is really difficult to know. We all know about Remploy being closed. Although there were mixed feelings about that in many areas, those were very positive places for people to go to gain employment and have a sense of self-worth. I think the risk that we may have to stop doing our Routes to Work project, because the funding has to go into more care needs, really is something that –

**David Ward MP**

Lynn, did you have a local Remploy closure?

**Lynn Travis**

Yes, we did.

**Heather Wheeler MP**

We did.

**David Ward MP**

Bradford did.

**Lynn Travis**

Oldham did and Bradford did. Yes, there were really good projects. I think it is like everything. To say all of them were not fulfilling a good purpose was wrong, because they did fulfil a huge purpose. It was not day care. It was actually giving people real motivation and reasons. As Charles Walker said, local authorities are really on the front face with people, and most of us involved in the day-to-day issues see that small achievements that we take for granted, like being

able to learn about how to use money, and how to get on a bus to go somewhere themselves, and to then get a certificate for that at an Oscars ceremony, means so much. It helps people to develop that independence. Those are the real stories that we see day to day: individuals who benefit from the services that we offer, and the opportunities we offer for people to develop and grow.

### **Sarah Lambert**

With Remploy and the idea of closing the factories, the discussion has been around moving the money that was spent on Remploy into access to work and into other things, to actually support people into mainstream employment, but for those individuals that were actually there, what happens to them; particularly people with autism who were in some of those factories? Routine is very important for people with autism. To suddenly have to stop that during the transition process out of a Remploy service is particularly challenging. Whether those same people are going to see the benefits of the funding that has been moved from there and into other areas is not clear as yet.

### **Heather Wheeler MP**

Work in progress.

### **Sarah Lamber**

Yes.

### **David Ward MP**

This question seems to be areas that you could. On the Education Select Committee, we have recently been looking at the SEN clauses in the Children and Families Bill. That is the idea of pooling budgets, with the replacement of statements in education and health. It always seems to be that health is the difficult bit in terms of the joined-up use of budgets, in my experience. You could get the local authority involved on the social side, and of course on the education side. It is getting the health provision, because it is a different system. Looking back to strategic partnership days, when there was a call round the table for people to pool budgets, it was always the local authority that –

### **Baroness Eaton**

Yes, it was.

### **David Ward MP**

– perhaps even the local authority and the strategic board that seemed to proceed with it. It is that difficulty, really, of getting the pooled budget. Because the different agencies and organisations have their own targets themselves. It is great within an organisation, where you can pool budgets from different departments and then save, but when it is different organisations, it is more difficult. ‘We, by spending a bit more money, can save you a lot of money. How does that help us, when our budgets are being cut?’

**Lynn Travis**

That is what I said about the fruit falling in someone else's garden.

**Baroness Eaton**

It is a little bit like when we had a Staying Put scheme for women experiencing domestic violence. It was a pilot and everyone thought it was a brilliant idea, and it saved the police an enormous amount of money. But because it was not one of police targets at that time, they could not actually make any contribution. So the local authority could not continue it. Do you remember that? That kind of thing is so frustrating.

**Sarah Lambert**

It is really about matching up the different incentives, from a central pot. Because you have got various different outcomes and frameworks that the health service has to deliver, and social care has to deliver. But if they do not match then they are going to be going in different directions. So how we can join that up is a key issue.

**Heather Wheeler MP**

Sarah, have you got a thought?

**Sarah Pickup**

Yes. Of course, there are pooled budgets out there. We have a £350 million pooled budget in Hertfordshire, which has been there since 2001 for mental health, learning disability, drug and alcohol services. So it is not un-doable, when you can align your objectives. It has been harder, in the sense of, 'We could prevent hospital admissions, if only we did more of  $x$ ' – so, the old people's agenda.

It is partly because health works with conditions, although they are shifting towards a focus on the whole person. While they were thinking about diabetes or coronary heart disease or this or that, it is quite hard to do something generic around a group of people. So that is important. But I do think there is some real scope with Health and Wellbeing Boards. Health and Wellbeing Boards are covering children and adults. I think that in the history of pooled budgets, it has been harder to integrate health money into children's services. Some places have done it, but there has been more in adult services. But the Health and Wellbeing Board brings all of that around the same table.

The difference with having CCGs around the table – who are GPs in their day jobs – is that they see Joe Bloggs coming into their surgery on Friday and they see what Joe Bloggs' needs are. Then they are responsible for strategic commissioning, and what they do then is link that strategic commissioning to what Joe Bloggs needs. That is the same as local authorities. We have individuals coming through the door with needs. So when we are commissioning, we are thinking about how the needs can be met. What I have seen locally – and colleagues feed this back as well – is some quite fast movement to make things happen which may have taken, and did take, historically, a lot longer.

We have got an integrated point of access in Hertfordshire for GPs, because GPs want one phone number to ring for community health and social care. They did not historically think they could access social care – because they once phoned them 10 years ago and could not get through, or something – and that was then the story. But once we showed we could do it, they all funded it and it was done like that, because there was no reason not to. ‘If it works, then why would we not do it?’ is now the story. Some of the same things will apply with children. Some of the therapies coming together, like speech and language therapy, and some of the work around disabled children will hopefully move forward. It will not be the same in 152 places, but I do think that there is hope.

### **Heather Wheeler MP**

Just to finish off then, because we have done really well for time, I do not know whether we have really talked about the carers and the families. I know it must be incredibly difficult for all of you to bring people into this, because you are almost dealing with big institutions and a proper policy area that you look after. I appreciate that you have got your outreach work and everything else, and your amazing society that you are here representing today. How do you link that in? How does the preventative care link in with the carers and families?

### **Lynn Travis**

It is vitally important. They are the ones who are shouldering the main burden – I do not think burden is the right word, but the main responsibility, the main pressures. It is about giving them support and also offering them respite, and the ability to have somewhere to go. It does not have to be a centre, but they need somewhere they can go, somebody they can turn to for advice and support and know that their questions are going to be answered, and that their needs are going to be met – not only for the person they care for, but also for themselves. That is quite often where a lot of care in the community falls down, when the carers lose hope or they find they are unable, for all sorts of reasons, to cope. The mental health pressures and the financial pressures on carers can be quite substantial. So when we are talking about people with disabilities, we are also talking about the families and the carers, who are just as much in need, and just as vulnerable, as the person they care for.

### **Sarah Pickup**

I would say that the provisions in the Bill on carers – such as the requirement to assess and provide services – are very welcome. One of the best things we can do for carers is enable them stay in work. So it is not all about services; it is about enabling them to live an ordinary life with the support that they need. There is actually a business case for supporting carers. I have had an excellent graduate trainee in Hertfordshire who has produced a business case that shows that you actually save money if you support carers as well. On the back of that we are setting up carer-friendly communities and carer-friendly hospitals with some investment agreed by members of the council. It is like most things. We talk about social care as a burden, and actually it is a big industry as well. It creates jobs, carers make a huge contribution, and actually a lot of them are employed and could stay employed and add to the economy, if we support them properly.

### **Sarah Lambert**

I think just to add to that, when we talk to the parents of people with autism, usually the things that they are asking for are things for their sons and daughters. Once those low-level services are in

place, those individuals can contribute a lot more to society; they are much happier in themselves and are able to work and to carry on supporting their son or daughter as well. So a lot of parents will say, ‘If you get the right support for my son or daughter, then I will need a lot less support myself,’ although respite is something that people do call for as well.

### **Heather Wheeler MP**

Ladies and gentlemen, thank you very much indeed for coming along today. We have rattled through everything, but we have got some tremendous thought-provoking answers and some great positive ways forward as well. On behalf of the APPG and the inquiry team, thank you very much for coming along. I hope you felt it was a good hour out of your lives.

### **Lynn Travis**

Thank you for giving us the opportunity.

## **Funding Social Care**

### **Members:**

*Anne McGuire MP (Chair)*

*Lord Tope*

*Charles Walker MP*

*Baroness Uddin*

*David Ward MP*

### **Witnesses:**

*Dr José-Luis Fernández, Principal Research Fellow Personal, Social Services Research Unit, London School of Economics (LSE)*

*Jonathan Carr-West, CEO, Local Government Information Unit*

*Sue Brown, Head of Policy, Sense*

### **Anne McGuire MP**

Thank you very much for coming this afternoon. This is the fourth of the sessions that you have. My name is Anne McGuire. I am one of the co-chairs of the All Party Disability Group. This is a joint inquiry with the All Party Disability Group and the All Party Local Government Group.

I do not know if you know everybody, but I will quickly go around the table. We have Baroness Uddin from the House of Lords, Charles Walker MP, Lord Tope – we were talking about you in

your other manifestation a minute ago – and David Ward MP. We also have colleagues from Scope with us today. The reason I am going to push things just a little bit is that we are expecting votes both in the Commons and the Lords. Those of you who have been here before will know that everything stops for the vote, so I want to make this quite tight to time, so that we actually get the full discussion going. I know that David Ward has to leave for another meeting at four o'clock.

Can I just say a very special thanks to you for giving up your time to come along and help us with this inquiry into adult social care for working age disabled people? It is an area that sometimes seems to get neglected, as we concentrate very much on social care for older people. I am going to ask David to kick off with our first core question.

### **David Ward MP**

Thank you very much, Anne. On that very point really, there has been general approval of the principles within the draft Bill, particularly regarding the cap on lifetime contributions, but very little at all so far, in my view, on how it will actually affect those of working age. So that is the only question: the cap and the benefits you believe it will bring, or maybe, not so.

### **Jonathan Carr-West**

Just to tell you who I am, I am Jonathan Carr-West. I am the CEO of the Local Government Information Unit. We are a think tank and membership body for the Government looking at innovation and transformation in public services. The short answer to your question is 'Little or not at all'. Dilnot had a mind to help people of working age, but I do not think that the cap was designed primarily to benefit them. As Scope have pointed out in their work on this, many, if not most, disabled people of working age will not have had a chance to build up significant assets. Therefore an asset protection cap is of little value to them.

There is a broader question of how much value it is to anybody. One of the things that gets missed in consideration of Dilnot is what it covers. It is taken that this is absolute protection of your assets. People forget that, if you are entering residential care, you will still have to pay hotel costs, food, and accommodation. It only covers the costs of actual social care. You still have to pay the difference – after you have used your £75,000 – between the actual cost of your care home and the council care home rate – which, in many places in the South East, is quite considerable.

There are also issues related to the asset threshold. There are issues about the lower threshold, and what you pay before you reach the maximum. So even under Dilnot, people are still going to be faced with very significant social care costs. While Dilnot is beneficial for many people, the way it is talked about gives the slightly false impression that it is this absolute protection of your assets up to £75,000. That is not the case whether you are an elderly person or a disabled person of working age. So I think there are real questions about how far the cap will benefit that population.

### **Dr José-Luis Fernández**

If you want to know what the likelihood is that the cap will benefit someone, there are two factors. One is: are they likely to use services up to whatever the cap is? £75,000 is a lot. It is £72,000 now, but that is still a very high figure, certainly for older people who are going to spend several years in residential care. On the other hand, younger client groups tend to have care packages which are more substantial than those of older people. From that point of view, I think that perhaps

they are going to hit the cap, all other things being equal, more quickly. However, the second condition is that you have income and wealth, and you are going to be paying for that care privately – you are not going to be helped by the means testing system.

That is the issue facing many people in the younger client groups. Many will not really have had an opportunity to accumulate assets, such that they are not covered by the current means test, and that is reflected in two ways. In Andrew Dilnot's costings, the cost that is associated with implementing the cap for people with learning disabilities or physical disabilities is much lower than for other people. Most of the money would go towards the older people's group. And actually, if you look at the relative contributions that those client groups are making in terms of the gross spend by social care departments at the moment, that is much lower, at about 5-7% for one of the groups. So it is much, much lower.

So the key question for this group is not how their care gets paid; because if they make it into the system, many of them are getting it with very small levels of payment. It is whether you make it into the system. If you do, then you are going to be supported almost completely by the state in terms of financial cost. So Dilnot will bring more demands into the system, and we still do not know how exactly it is going to be funded. The question is what the knock-on implications of bringing Dilnot into the system are in terms of pressures. We know that demand in terms of numbers of people hitting the system is growing. It is growing at 2% or above. So that really accumulates very quickly. For people with learning disabilities, this is a particular concern. Therefore the worry is that the local authorities will continue to ramp up the eligibility criteria, as they have been doing in the last few years.

As I say, that is really the key question for these groups: whether you make it into the system. There are two conditions to make it into the system. One is your needs, and the other is the financial means test. The means test is not really a problem. It is more the needs eligibility criteria. If that goes up, then a lot of people could be excluded from the system.

### **Anne McGuire MP**

Is that your sense as well, Sue?

### **Sue Brown**

Very much so, yes. I think there are a small number of working age disabled people who will benefit particularly. It has not yet been decided where the cap will sit for working age people, less than £75,000. Dilnot recommended a zero cap for people below the age of 40. There is a very small number of disabled people of working age who are in work and who are, for instance, trying to save enough money to put down a deposit on a house and buy a flat. In the South East, the capital threshold is now making it more difficult to save that much money, because they have to save an amount that triggers them into having to pay for their care and support. But that is a really, really tiny number of people.

I think the real question for working age people is eligibility: are they actually going to get any support at all, and not who is going to pay for it. One concern is that for working age people, it is partly about eligibility, but it is also about the general squeeze on budgets that we are experiencing at the moment. In assessments, we are seeing increasing numbers of people being charged for things that they were not before. Those sorts of things are beginning to happen. If the Dilnot capping system is brought in and it is not sufficiently funded, we are actually going to see that get

worse. The people who will get hit by that will predominantly be people in the means-tested system. For quite a lot of working age disabled people, that is a real risk.

**Anne McGuire MP**

Is that squeeze becoming more obvious as some of the benefit changes come in, about the difficulty for working age disabled people to build up any asset base?

**Sue Brown**

I think it is not so much about the benefit system as about the combination of various demographic changes that increase demand – both among older people and particularly among younger people with learning disabilities – and the cutting of local authority budgets, which hits services across the board. It is that squeeze which is pinching on everyone in the means-tested system. If you are also finding your benefits cut, though, you have less leeway for taking on any shortfall that you are being provided with by social care.

**Anne McGuire MP**

Does anyone wish to respond?

**David Ward MP**

There is the issue of local authority rates, in terms of those who are self-funding or through third-party contribution to top it up.

**Jonathan Carr-West**

Yes. If you are a self-funder in residential care, then under the Dilnot proposals, you hit your cap at £72,000 or £75,000, and you no longer have to pay your social care costs, but you still have to pay the difference between the local authority rate and the rate of the home you are actually in. That can be quite substantial. If you are in the South East of England, there will be many places where the actual costs that you are paying to the residential home will be in excess of £500-1,000 a week, and the local authority rate will be £350 or £400. You are still liable for that top-up, even after you have paid your cap. So there are still quite considerable costs to self-funders.

If I could just come back to the point about local authority budgets, the question that Sarah raises about where the funding for Dilnot comes from is crucial. It does create massive extra pressures on local authorities. Crudely, it hits both rich authorities and poor authorities. Most people's main asset base is in housing. So for example, the cap will affect areas where you have lots of people who have houses worth more than £100,000. Those people are not currently the local authority's problem at all. They are self-funders, they do not have to worry about them or have to pay. But they will now have to pay some of their costs, after £75,000.

So if you are Surrey, for example, that creates a massive set of people, who you previously did not have to pay for, but you do now. On the other hand, if you are somewhere with much lower property rates, you have a lot of people in properties worth between £23,500 – the current threshold – and £100,000. At the moment they are not your problem, because they are self-funders. They

will now become your problem. So there is a double squeeze on local authorities in terms of what the Dilnot proposals will do to their budget.

So for me, the question is actually not so much, 'What are the direct implications for disabled people of working age', because for most of them it is not going to be that relevant. It is 'What is the indirect implication of the impact it has on local authority budgets; the squeeze it puts on other services; the squeeze it puts on the sort of preventative and support services that we know people need so that they do not need more acute interventions?' That, for me, is the real question.

**Charles Walker MP**

What is the average length of stay?

**Jonathan Carr-West**

In a residential care home?

**Charles Walker MP**

Yes

**Jonathan Carr-West**

For an older person it depends. Self-funders tend to put themselves in too early; the average is about four years.

**Anne McGuire MP**

The average is less for those who are not self-funders?

**Jonathan Carr-West**

Because they are subject to more assessment by the local authority, they tend to get more support before they enter residential care. There is a phenomenon where there are quite a lot of people who do not have much interaction with the local authority, until they reach some sort of crisis point, generally a hospital admission, and then they put themselves into residential care and pay for it. A quarter of them end up depleting all of their resources, and falling back on the local authority.

**Anne McGuire MP**

Have there been any analyses about how long a period £72,000 will buy?

**Jonathan Carr-West**

I think Dr Fernández will know that better than me. It will depend on people's conditions.

**Dr José-Luis Fernández**

How fast are you going to reach £75,000 once you are in residential care; that is a relevant question. There you have to remember that you are going to be paying two things. You are going to be paying the accommodation costs of £10,000 per year – which are the responsibility of the individual. Every year you are going to be paying that. A year of residential care costs around £30,000. It varies tremendously from one local authority to another. It also varies depending on whether you are a private payer or not. I was talking to some authorities who suggested that private payers are paying 30% or 40% more than local authority residents.

If you think about £30,000, which is the local authority rate, minus £10,000, that is £20,000. So you have to be spending three to four years in residential care before you qualify. The median length of stay in residential care is about a year. The mean is a bit more than two years. So you are talking about very few people who will remain there after that. For the younger client groups, the length of stay can be much longer, but I am talking about older people, which the Dilnot proposals were targeting primarily.

**Anne McGuire MP**

But for younger people, that might be a longer period?

**Dr José-Luis Fernández**

Much, much longer.

**Anne McGuire MP**

Much longer, obviously.

**Charles Walker MP**

Just remind me, because I saw the cost of this in the newspapers and I have forgotten, what is the estimated annual cost?

**Dr José-Luis Fernández**

On the basis of Dilnot – which is a £35,000 cap of course.

**Charles Walker MP**

No, no. Global costs. Because Jonathan, you are saying that this additional money is going to have to be found by local authorities, and I just wonder, is it £2 billion a year additional money that will have to be found by local authorities?

**Jonathan Carr-West**

The Government is talking about providing funding for it, but it is not yet clear how much that will be. I do not think we know at the moment, because we do not know what the cap will be. Under Dilnot's proposals, which included a £35,000 cap, he was estimating – £1.2 billion?

**José-Luis Fernández**

About £1.4 billion for older people, and £0.4 billion for younger client groups.

**Jonathan Carr-West**

But obviously we are now looking at quite a lot more than that, because we are suggesting a cap that is significantly higher.

**José-Luis Fernández**

It is £1.7 billion, plus £0.4 billion.

**Baroness Uddin**

To a certain extent we have already made some reference to this, but I would like you to elaborate, if possible, about the means test for residential care, which is going to go up to £123,000. Is that going to be significant for working age disabled people? Interestingly, given what you have already said, I can already hear your heartbeats about this.

**Dr José-Luis Fernández**

The issue is very similar. It does change some of the incentives, in the sense that this was really designed for people who have low incomes, but a moderate amount of wealth, perhaps living in the North where housing wealth might be more limited. Therefore this would help them not deplete. In terms of younger client groups, I think it might help people who are in residential care, for example, have more of an incentive to accumulate assets, which would help them. But really, the numbers of people we are talking about here who would benefit are very, very small.

**Sue Brown**

The raising of the means test threshold is only for people going in to residential care. So in order to benefit from that, you really need to own a house or some other really substantial asset that you are now moving out of into residential care. To be honest there are not very many people of working age – there may be some people who are just below retirement age, or perhaps maybe have taken early retirement, but the vast majority of working age disabled people, if they own a house, live in it now. So really, that threshold is going to be pretty much irrelevant.

**Jonathan Carr-West**

I think you have to bear in mind that Dilnot is a very circumscribed answer to quite a limited question. It is to address a real unfairness in the system, where if you have assets of a certain value

and you happen to get dementia and go into social care, you will lose everything you own, and if you do not have any assets you will get the same sort of care without having to pay for it. Essentially, if you end your life with Alzheimer's, you lose everything, and if you end it with cancer you get to keep your house. It is that unfairness that Dilnot was set up to address.

What became clear when we did our inquiry into funding social care for older people is that Dilnot is part of the problem. Dilnot will be adopted *faut de mieux* – there is nothing else out there, it is the only detailed proposal on the table – but it only answers a little part of the problem. It does not solve the funding questions for social care. I think there is a danger that Dilnot will obscure the whole debate, because we will say 'Dilnot, Dilnot, Dilnot.' But actually, it is really a very small part of the overall picture.

### **Baroness Uddin**

If Dilnot was not on the table, what would you prescribe?

### **Jonathan Carr-West**

Well, I think that is the big question you were going to ask. So I can come back to it if you want. The point is that we do have to look beyond Dilnot. We have to think what a future system looks like. Essentially, we need a much more preventative system – we can talk about this in more detail – which is much more about building capacity for both elderly people and disabled people to care more for themselves. We need a system which is much more about an asset-based approach that looks at the civic community capacity that we have to support people, that commissions for outcomes rather than just paying for time blocks.

There are all sorts of things we can do. Effectively, we have to manage that divergence between demand and resource. I think part of the problem is that the concentration on Dilnot stops us thinking about those things, because there is such a live political debate on Dilnot, and we forget that it is only doing a little bit. He never intended it to solve everything about social care for disabled or elderly people. It was not designed to do that.

### **Charles Walker MP**

I think that is an interesting point. It suits politicians to come up with solutions and say 'Move along. Problem resolved.' But as you rightly point out, it is only a very small part of the jigsaw, which has been partially resolved.

### **Jonathan Carr-West**

It is an important part.

### **David Ward MP**

I think we should get some idea of the size of this small part of the jigsaw. Is it a small part of the jigsaw?

**Jonathan Carr-West**

Well, I think it is a small part of the overall jigsaw. The point is that Dilnot addresses that fairness question –

**David Ward MP**

Is it not a big part of the jigsaw?

**Jonathan Carr-West**

I think politically, it is a big part, but what it does not do is resolve the overall resource question. So it leaves you with a £2 billion cost now – and it is an expanding cost. Part of the danger in terms of working age disabled people is that the elderly population is expanding so fast – it is due to expand 100-fold over the next 60 years. There is a danger that the system constantly builds up costs in protecting these people's assets – which may well be a thing you would want to do politically, of course – and that money has to come from somewhere. And Dilnot does not provide an answer to that question.

Dilnot creates a cost and says, 'Money should be bought from somewhere else to fund that'. I think if you want to address the real issues, you have to look at demand management. And that is about real demand management. It is not about, as Dr Fernández and Sue have both said, shifting eligibility criteria. That does not manage demand, it just changes who gets help. But there are ways, particularly for local authorities, to put more money into social care, rather than acute healthcare, more money into preventative services, more money into capacity-building, then you start to actually manage the problem. The whole problem, rather than just that fairness issue. The fairness issue is important, but it is not an answer to the funding question.

**Anne McGuire MP**

Dr Fernández, you have done some work on individual budgets. Is that going to be part of the solution?

**Dr José-Luis Fernández**

We were part of the national evaluation of the individual budget pilot. That was a very interesting evaluation, which had mixed results in terms of the cost-effectiveness, of the success of these –

**Anne McGuire MP**

Older people did not like them?

**Dr José-Luis Fernández**

Yes. The results were very dependent on client groups. We found that older people struggled a little bit more than the younger client groups, but that the younger client groups were having better outcomes, with no additional cost. So they were looking cost-effective – so that might be one way forward in terms of improving the efficiency of the system. But of course you have to think about the differences in the rates that local authorities pay and individuals pay. That is in part because

local authorities are very big consumers, and have this monopoly power in the market. Therefore the itemisation of the commissioning is also dangerous. What you need is not just a blanket direct payments policy, but accompany that with policies which manage the market and the local authority, and which provide guidance for people on how to purchase the services. In times when the money is running out, that is the sort of service which goes very quickly.

### **Anne McGuire MP**

Of course, that is a challenge for individual disabled people as well. They effectively have to project manage themselves, and that is very difficult.

### **Sue Brown**

Yes. I think there are some people who are well-equipped to do that. It is hugely beneficial for them to be in control, buying their own services. There are other people for whom that is really difficult, for a variety of reasons. They do not have those sorts of skills. If you need to employ someone and in your usual work you do not manage people, that is actually a huge challenge. From a census point of view, a lot of those support services really do not understand how to support people with sensory loss – people who cannot read the payslips and do the payroll and all those sorts of things. There is a huge challenge for that group of people as well. So I think that whilst direct payments are massively beneficial to quite a lot of people, there are also groups of people who do not need that hassle – as you say, effectively project managing your own life. I find it hard enough to manage my own life. If I then had to manage a support worker as well, that would be a real challenge.

### **Dr José-Luis Fernández**

To be fair to the Department of Health, I think they have recognised this to some extent, and that is why personal budgets are not just direct payments. There is a range of processes for implementing personalisation. But they do require resources, to support people in making the right choices.

### **Jonathan Carr-West**

They also require a range of skills, both among clients and among the local authorities who support them. I think you do see quite a lot of variation. Certainly, we have been out talking to local authorities about direct payments and about personal budgets – and they have been saying that essentially, with some clients this is just a fiction. In our authority everyone has a personal budget, but for some elderly people, some people with disabilities, but we are actually just deciding for these people, because they just do not want to. I think this does illustrate that there are not any ‘one size fits all’ solutions to this. You have to have a range of tools that you can apply differently to different client groups and different people.

### **Baroness Uddin**

Very quickly, given the explanation that you have just furnished us with, you are almost painting a picture that those who are really *au fait* with all of them and keeping their eyes and ears hooked to the ground and on the television and into government policies and all that will benefit more. Earlier in the inquiry last week, we were talking about inequality of access to these services anyway, for black and minority communities. Do you have a view about how we can ensure that

even in this place, given that there is inequality of access anyway, for everyone, especially disabled people and older people, there is not more suffering, more lack of access, more inequality, for black and minority communities within this category. I just want to have a very brief response from you.

**Dr José-Luis Fernández**

The problem is that the sources of information that we use tend to be quite small. To look at even smaller divisions of that small sample then becomes very difficult. So there are suggestions that there are inequalities in access to services, and the extent to which different types of service are used by different members of the community. But I have not seen any very strong evidence, in terms of social care services, to quantify that.

**Baroness Uddin**

That is because they are not accessing the services. The suggestions –

**Dr José-Luis Fernández**

There is that too. To be honest, a very important lesson is that for private payers, we know very little about what sort of care they are using. For example, we do not know what the distribution of income and wealth among physically disabled people, or people with learning disabilities, is; it is almost impossible to find out.

**Anne McGuire MP**

Jim, did you want to follow up on anything?

**Lord Tope**

Could we go on to my next question?

**Anne McGuire MP**

Yes.

**Lord Tope**

We are almost anticipating it, really.

I want to move really from problems to solutions. To copy your words, let us forget Dilnot for these purposes. What we cannot forget is that the funding outlook is not good. You have already mentioned that there is going to be a huge increase in the number of elderly people in future years. So what solutions would you like to suggest, within that context, for working age disabled people?

**Sue Brown**

If we said we were going to put some money in to the system, because Dilnot is going to cost some money, what would we spend it on? I think there is a serious question about whether Dilnot is what

you would have gone for first. I would say that one of the things that is an issue for working age disabled people is that eligibility threshold. Actually what we need to do is drop the eligibility threshold, so that people with moderate needs are actually getting those needs met. There is a lot of evidence that that will prevent people from developing higher level needs if we get in quickly and support them at that early stage. The local authorities that still fund that low level of support can afford that because the second someone has a need, if you get in there and give them some level of support, you are developing that –

### **Lord Tope**

But has the number of local authorities saying they are meeting moderate level needs not reduced considerably, not surprisingly, in the last two years?

### **Sue Brown**

It has indeed, yes. I am not sure that there is any evidence that that has significantly reduced the amount of money that they are spending on social care – for a whole variety of reasons that are quite complex. I think meeting those lower level needs is one of the ways in which you need to try and address that system. The other problem I think we have is that we are constantly thinking that social care is this burden, this drain on resources, taking money out of the system. I think we maybe also need to flip that on its head and say, ‘Actually, the social care system is a bigger employer than the construction industry.’

In the middle of a recession, when we have massive unemployment, if you really want to spend in a way that will reduce that, then actually social care, where most of the costs go on labour, is a good investment. It also ought to be seen part of the central infrastructure of our economy. So when you support a disabled person, you are potentially enabling them to work when they might otherwise not be able to. You are also enabling carers to stay in work, to be more reliable employees, and so on and so forth. You are creating lots of jobs in social care.

So I think part of the problem is that we are constantly looking at this as a drain, seeing it as being like the benefit system when you are paying out money and basically not getting very much for it. If we saw this as essential infrastructure for the economy, and recognised what it can deliver in terms of support for disabled people, and employment within the care sector, we might start to think about that slightly differently. That is before we come on to talk about some of these things like a more preventative approach, delivering services in a way that will develop people’s skills and resilience, and enable them to continue to live independently.

### **Anne McGuire MP**

Does that answer your question about where the funding solutions are going to come from, though? I think it gives a very good economic argument, but I am not sure if it actually squares the funding circle. So maybe a local authority representative could help us here.

### **Jonathan Carr-West**

I think it begins to. There is there is a lot of evidence – Dr Fernández has done a lot of work on this – that shows how much money you save, particularly in healthcare, through spending on prevention. There are different figures you can use, but every pound you spend on preventative

care saves about £2.50 or something. So I think if you are being very crude about it, what you need to do is the politically unthinkable: take money out of the NHS, and put it in social care and give to local authorities to spend sensibly and preventatively on keeping people out of acute need. That is where you make the saving. That money is sitting there in the NHS, being spent on things that we should not have to spend it on.

Every time someone goes into hospital, thousands of pounds are racking up: chink, chink, chink. That is where the money is: already in the system. So it is not all about putting extra money into the system. It is about taking the money that we are spending badly and spending it somewhere else, where it will be more effective. We talk about prevention as a way of saving money, but it is really important to remember that it is also better for people.

Most of the work we have done on this has been in relation to elderly people, but I think it parallels across. People always talk about the £30 grab rail. 'Put in the £30 grab rail and the old lady does not break her leg, and does not go to hospital. If she was in hospital for the week, that would be £14,000.' Great – you have saved the best part of £14,000. But it is also better not to have a broken leg. So it is looking for those sort of win-win solutions, where actually a preventative approach that builds people's capacity to be independent and look after themselves saves you money. I would suggest that that money is in the NHS. That is very difficult politically, because it is very hard to take that money out of health and spend it somewhere else.

### **Lord Tope**

The House of Lords has just done a report on ageing which very much makes that point, among a lot of others.

### **Charles Walker MP**

Just playing devil's advocate here, I know a lot of health economists and you must know a lot of health economists. (Jonathan Carr-West intervened - I hang out with very few other people.) There is a lot of misinformation about smoking. People should smoke less, because it is not a good thing for themselves or for those around them. But at the end of the day, all the economic statistics around smoking that have been trotted out in Parliament generally report that smokers pay huge amounts of tax and tend to die younger; some of them might just spark out. So actually the gains to the health economy from people stopping smoking and living longer may be illusory.

Now here is the issue. Prevention is a great thing. But if you have prevention, you will offset that through longevity. So is this almost a zero-sum game, as there are all sorts of costs attached to longevity? I am not trying to be difficult here, but maybe the solution is going to have to be out of general taxation. Somewhere along the line we are going to have to find more money.

### **Jonathan Carr-West**

A couple of things. I think the problem is that there is no tax on being old, or on being disabled. So you do not have that equivalent revenue generation. Smokers have a particular tax income. The problem is that it is not about longevity, because we still keep people alive but this time we just have a medical intervention which contributes to the same amount of longevity for the same cost; we are just spending more on it. So I do not think it is the equivalent situation, because the costs are more fixed, and there is no equivalent revenue.

Do we need to find the money out of general taxation? I am moving slightly away from disabled people to elderly people, but if I could just share this: there are currently 10,000 people in this country who are over the age of 100. According to the Government Actuary's Department, by 2071 there will be 1 million people who are over the age of 100. I think everyone in this room would probably qualify by 2071.

**Anne McGuire MP**

Some of us will be well away by then. We will look down.

**Jonathan Carr-West**

That is not going to be 1 million 100 year olds doing Salsa lessons and skipping around the golf course and going on cruises. It is going to be a million people with very, very complex needs. I would suggest that if we think we can find that sort of resource out of general taxation, then I –

**Charles Walker MP**

There is a huge cost to longevity, which we have to face up to, is there not?

**Jonathan Carr-West**

Yes. We have to face up to it.

**Dr José-Luis Fernández**

There have been a lot of studies looking at the impact of an ageing population on health and social care expenditure. The key is not the number of people you have got who are over 100 years old. It is the kind of spending at the end of your life in a dependent state. That is shrinking in some countries, and it is increasing in other countries. So you could have many more older people and actually spend less, if you are reducing the number of years that people spend in a disabled state at the end of their life.

**Jonathan Carr-West**

Which again brings you back to prevention, and spending small amounts of money on reducing that.

**Anne McGuire MP**

I am conscious of the fact that we are back on Lord Mackenzie, which means that he might be winding up. So I am going to ask Charles to move us on to his next question, and if the bell doesn't go, then we can have a general discussion. Forgive us for having to do things this way.

**Charles Walker MP**

I think we have almost started on my question, which is: what can we do to make funding go further? We have opened up that discussion. We had a very interesting chat this morning with

people from local authorities, and actually there is a lot of blurring of budgets that has been negotiated at a local level between local authorities and NHS providers. I think that is a very healthy thing. For example, when an urgent care centre needed to be built, my local authority actually put £1 million of its own funding towards it, because it realised that that was good for the community. So what can we be doing; not just to make the funding go further, but actually to make sure there is more funding, and that the funding that we have is spent wisely and appropriately? I do not think that we can do that – this is now more of a statement than a question – unless we have greater integration between service providers at the coalface.

### **Anne McGuire MP**

I am going to ask you, Dr Fernández, since you straddle both health and social care. Given the challenge from local government that some of this NHS funding should come across, maybe I will give you the first spot on this one.

### **Dr José-Luis Fernández**

If the idea is that the budget is limited and that we have to play with it to use it best, then we can talk about several things. There is efficiency – and we have talked about how improvements to efficiency can perhaps be brought about through personalisation, for those people that it works for – and there are some caveats there. We have talked about integration between health and social care. That might work, but we really need to improve our understanding of how to go about implementing that, because it does not always work.

One of the challenges – and we have alluded to this – is closure of services. If you want to realise reductions in expenditure, then some services are going to have to close in one area. A hospital might have to close: that is not politically a very easy thing to do. And incidentally, if you increase healthcare expenditure, you reduce the need for social care as well. There is very good evidence that if you give somebody a hip operation, they are going to need less social care. So it is a two-way relationship.

I would say, and this is not politically easy either, that although we often talk about health and social care, there is also the benefits system. The benefits system is spending a lot of money on supporting people with social care needs, and on a very different basis, and with no coordination between the two. I think there is a lot of money there that could be used in a more constructive way in the future. But it is a challenge. Reforming DLA, which is being done at the moment, or a tenant's allowance are not easy things. When you compare the amount of resources that we are spending as a whole against expenditure by some other European countries, though, when you add it all up, it does not look too bad.

### **Anne McGuire MP**

Does there need to be a rebalancing between the amount of financial resources that are invested in older people and those that are invested in younger people? We do tend to protect, and it is a political hot potato, all of the financial support that goes to older people, and somehow younger disabled people are maybe left at the bus stop. I do not know if it feels like that.

**Dr José-Luis Fernández**

If you look at expenditure in recent years, it has been going down. But local expenditure has been going down much faster than social care expenditure. Social care expenditure for younger people has been going down less rapidly than that for older people. So actually, it is younger client groups that are being protected, relatively speaking.

**Jonathan Carr-West**

I am interested in the challenge of how we can get better integration at the coalface. I think if I was playing devil's advocate and pushing back to you guys as national politicians, I would say that we are actually quite good at that out there. Will DWP and DH match that level of integration, and will they support it? I think that is the crucial question.

**Charles Walker MP**

I would just say that at the previous meeting, I said that my local authority, Hertfordshire and Broxbourne, is far better at doing it than national Government is. I think local authorities have led the way in innovation and service delivery during the challenging times we have experienced over the past three years. I think that national Government, rather than lecturing local government, could actually learn quite a lot from local government, so I am with you on that entirely.

**Anne McGuire MP**

Have you looked at the Scottish model, where there is now going to be a far greater integration of health and social care budgets, with a joint approach between local authorities and the equivalent of what we call health boards?

**Jonathan Carr-West**

I have not looked at it in detail but I am aware of it. From my brief glance at it, it looks like an interesting way forward. There are different ways of doing that but I think that some –

*[Division bell sounds]*

**Baroness Uddin**

I was just going to say that I think where health and social care has been successful is that there are many good local authority practices like your own.

**Lord Tope**

I am going to have to leave the room in a minute, but community budgeting is one of the things that I know you have looked at. There must be a lot of scope there for more efficient use of resources.

**Jonathan Carr-West**

Yes, there is. What it needs is for central Government to walk through it.

**Lord Tope**

Yes. I was jumped into asking that question by exactly the point that it is actually central Government Departments that are holding that back more than those at the local level.

**Jonathan Carr-West**

I believe that is right. Of course, there are problems with it at the local level as well, nothing is perfect.

**Lord Tope**

When people's budgets are diminishing, they want to hang on to what they have, rather than to share what they have. It is perhaps understandable, but not helpful.

**Anne McGuire MP**

Is that what you feel as well, Sue: that the further away you are from Westminster, the better the joined-up services are? Lord Tope, if you have to run, then do

**Lord Tope**

I do. I was just going to say that I am a London councillor and Westminster seems a very long way away to me too. It is not about geography.

**Sue Brown**

I think it is inevitable, when you look at 150-odd local authorities, that the picture is very patchy. There are some that are very good and some that are really not very good. Some are very good on  $x$  but not on  $y$ , and some are the other way around. So I think it is not necessarily that all local authorities are doing this brilliantly. Some of them respond to the reducing budgets by innovating in really positive ways. Unfortunately for disabled people, a lot of them respond to diminishing budgets by doing the same thing but badly, and introducing lots of ways of attempting to control money that are actually quite inefficient and expensive.

So instead of somebody having an assessment and getting some services that cost a certain amount of money, they go through a tick box RAS (resource allocation system) that gives them an indicative budget that turns out not to be enough. Then another budget gets sent to a panel who have never met the person before, who attempt to randomly chop 25% off the budget in the hope that they can get away with it. Sometimes they do get away with it, and sometimes you then go through the very expensive process of legal challenge to that decision. None of that is helping anybody, and it is not helping the local authority budget.

The other thing that I would say is that some of it is about integration of health and social care. But for working age disabled people, it is also about the difference between a person who is living on benefits, and a person who is in work. And yes, they are getting disability benefits, but they are not getting out-of-work benefits and they are actually being a contributing taxpayer. That is a different question. There is also a group of people with learning disabilities for whom losing a very small amount of support can end them up in things like the criminal justice system, which is extremely

expensive to send people into. So it is not just health and social care, it is also about the economy, work, criminal justice; there is a whole series of savings to be had from meeting some of those relatively small levels of need, rather than saying ‘Times are tight. Let us cut that.’

### **Jonathan Carr-West**

That is absolutely true, and local authorities need to be working across the public realm: across health, social care, housing, environmental services. You name it. It is not my job to sit here and blow the trumpet – or I suppose it actually is partly my job to do that. Some are awful. But I think the best practice that is out there in local authorities really is leading the way on this. What we need is for central Government to get behind that and say ‘This is how it can be done at its best. Let us support that integration.’ Then everyone else can start to emulate that as well. Because you are absolutely right. We need that joined up approach across the public realm – not even the public sector, the public realm, because actually it includes the voluntary sector, it includes the private sector; it is a very mixed provision. But we need that connection if we are to meet some of these challenges and enable some of this demand management.

### **Anne McGuire MP**

This is a point for Dr Fernández. One of the questions that I used to be asked when I was Minister for Disabled People was about the portability of social care packages and support. I think what you are saying is correct: that there are some good practices in local authorities, working with the voluntary sector and indeed the private sector. But what that does not do is in many cases is forward the ambition of independence, choice and control. If you are stuck in your patch, Charles, with a package that is really well integrated, and you want to move to a job in Westminster, and they do not have such a good system, then actually the independence is not there. As a young, working age, disabled person, you cannot make decisions in the same way as a young, working age non-disabled person. Do your investigations bear that out?

### **José-Luis Fernández**

What is easy to say is that there is a great heterogeneity in the services that are provided locally. There is no question about that. What is more difficult to judge is the defensibility of those. To some extent, if you are in London, you do not want to be providing residential care, because that is not going to be cost-effective. The coverage is very different as well. The proportion of the population that is going to be served varies tremendously across authorities as well. Then the question of localism, and what it is right for local authorities to decide to do comes into play. I am not sure that the extent of variability we are observing can be explained on the grounds either of local supply conditions or of differences in the preferences across local authorities. I think there is some difference, which is random, really. What do you do about this? The Bill is going to allow portability of your current package. But of course once you get to your destination you will be reassessed by local services. If you want to remove that, then you have to do away with localism. There is a democratic issue there to be resolved.

### **Charles Walker MP**

It is a very good point. Philosophically, I am a big fan of localism, because if I want to get things done with a variety of groups, and I want involve third sector organisations involved with disability, I find my local authority is a very good route to doing that. They have got good local

relationships, good local connections. Actually, I think there should be much more central Government devolution down to local authorities, because it is at a level that is small enough that you can actually make a difference to people's lives. There will always be people falling through cracks, but less people do at the local level, because you are going to be more aware of them – if that makes sense. But you are right: at the same time, if you have got a great package in Broxbourne and you move to Broxtowe in the Midlands, you will be subject to a different set of rules.

### **José-Luis Fernández**

Of course there is now the idea that there are going to be new minimum eligibility criteria across the land, but where are they going to be set? That is the key question.

### **Jonathan Carr-West**

This brings us back to all the arguments about the postcode lottery, and so on. There are issues there, but when you try and resolve that by defining some national standards, then you can fall into not quite a lowest common denominator, but a bit of a lower average. It is okay for things to look different in different places, as long as the service users – local people – have the democratic grip to have a say about what is important to them. For example, on your question about the balancing between older people and working age disabled people, there is no reason why that should not be a local decision about people saying 'Our priority here is that we have a lot of older people and we want to support them, and we think there would be different ways to support working age disabled people' or vice versa. People may want to say, in a particular area 'Actually, all our older people are minted. They have got big houses, they can look after themselves. The people we need to support are the working age disabled people.' There is no reason why that should be the same across the country.

### **Anne McGuire MP**

There is still a tension, though, between a working age, ambitious disabled person, who has the opportunity to move to another area for a better job – a career move – who might find that they cannot take their current package with them. So that is where the tension is: between the strategic objectives that there should be independence, choice, control and portability, and local decision making. If you move to another area, you might not meet the threshold.

### **Jonathan Carr-West**

That is right, but what I would suggest to you is that the attempt to fix that probably creates a situation that is worse for everyone.

### **Anne McGuire MP**

That is why we are having these discussions, because nobody thinks there are any easy answers. Sue, I am going to give you the last word on this.

**Sue Brown**

I think there have to be limits on the localism when you are talking about people's fundamental right to support for basic things to do with day-to-day life. It has always interested me why in the NHS it is called a postcode lottery and it is a bad thing, and in social care it is called local democracy and it is a good thing. The bottom line is if you can get support with maintaining your social networks in local authority A, and you cannot in local authority B, it has to be a bad thing for the people who live in local authority B. In my opinion, there have to be – for all disabled people, particularly those of working age – bottom lines. We need to say: this is a minimum standard of living and quality of life below which we will not let disabled people fall. That has got to be the minimum across the board.

**Anne McGuire MP**

So one person's localism is another person's postcode lottery.

**Charles Walker MP**

Gosh, there is a huge philosophical argument to be had here.

**Anne McGuire MP**

That is not bad for 55 minutes. Can I say a very sincere thanks to you? You have been very patient with us disappearing at various points. As you will have heard, an extensive report is being done as we speak, and all of that obviously will be published in due course. I do want to thank you for giving up your time to come here this afternoon. It has been an interesting and challenging discussion from three different perspectives, but three perspectives that in some senses actually dovetail as well. Thank you very much.

**This Transcript was produced by Ubiquis UK ( +44 (0) 20 7269 0370)  
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