

# The Joint APPG Inquiry into Social Care Reform for Working Age Disabled People 13 March 2013

## The Right to Independent Living

### **Members:**

*Heather Wheeler MP (Chair)*

*Tom Clarke MP*

*Sarah Newton MP*

*Baroness Wilkins*

*George Hollingbery MP*

*Baroness Uddin*

*David Ward MP*

*Baroness Eaton*

### **Witnesses:**

*Liz Sayce, Chief Executive, Disability Rights UK*

*Julie Jaye Charles, Chief Executive Director and National Ambassadors Lead, Equalities National Council*

*Jane Young, Disability Consultant*

### **Heather Wheeler MP**

Ladies and gentlemen, we are on parliamentary time; it is exactly two o'clock. Welcome everybody. I am Heather Wheeler. I am MP for South Derbyshire, and the reason I am chairing this particular session is that I am chairman of the Local Government All-Party Parliamentary Group. My background is as a councillor for 20 years over a 30 year span. What would be super is if everybody round this table introduced themselves, and then your good selves too.

### **Sarah Newton MP**

I am Sarah Newton, Member of Parliament for Truro and Falmouth; I am a Conservative Member of Parliament. Before I came to Parliament I worked for the International Longevity Centre in the UK with Baroness Greengross, who will remember some of you. Before that I was director of Age Concern England, responsible for campaigning and fundraising. I have a particular interest in this subject.

**Heather Wheeler MP**

This is Baroness Uddin who is just joining us; perfect timing. We will come back. Would you like to introduce yourself?

**Heather Wheeler MP**

I am still Heather Wheeler.

**George Hollingbery MP**

George Hollingbery, Member of Parliament for Meon Valley in Southern Hampshire. I was a councillor for 11 or 12 years, and was on the CLG Select Committee for two and a half years. I am a Conservative.

**Tom Clarke MP**

Tom Clarke; I am from Scotland. I am the MP for Coatbridge, Chryston and Bellshill. Before that I spent some time in Local Government, and was president of the Convention of Scottish Local Authorities. I was fortunate enough to reach the top of the ballot in 1986, and so I managed to get a Disabled Persons Act through, and then when I was elected to the Shadow Cabinet for two years, Tony Blair made me the spokesperson on disability. I have continued my interest since.

**Baroness Wilkins**

I am Rosalie Wilkins, and a Labour peer since 1999. My background is disability television with the *LINK* programme from the 70s through to the late 80s, with a number of documentaries. I am also interested in the voluntary sector disability organisations, including the National Centre for Independent Living.

**David Ward MP**

I am David Ward. I am a Member of Parliament for Bradford East and a Liberal Democrat MP; I was elected in 2010. I had a Local Government background for 26 years, and was a university lecturer for many of those years, but I was on Bradford Council as well. We have done a huge amount of work on the draft bill, and we distributed about 30,000 survey forms, and worked with many of the disability groups and groups for the elderly, to talk to them about the draft bill and the White Paper. We produced a report that was submitted to the Minister, to feed back on, in particular, Bradford aspects of the proposed legislation.

**Heather Wheeler MP**

Would you like to introduce yourselves?

**Jane Young**

Yes, I am Jane Young. I am a consultant and a campaigner on disability issues. I have a fairly extensive Local Government and voluntary sector experience, and I am currently supporting the Spartacus network, such as it is.

**Liz Sayce**

I am Liz Sayce; I am Chief Executive of Disability Rights UK. We are an organisation led by people with every type of impairment experience, and most of our staff are also disabled people. We are a national and pan-disability organisation.

**Julie Jaye Charles**

My name is Julie Jaye Charles; I am the Chief Executive of the Equalities National Council for BME disabled people and carers.

**Heather Wheeler MP**

Thank you very much indeed. Baroness Uddin, now you have caught your breath, would you like to introduce yourself?

**Baroness Uddin**

I have indeed. My name is Pola Manzila Uddin; apologies for the slight delay. I have been a councillor for eight years in Tower Hamlets before coming to the House of Lords; I have been here for 14 years. My primary interest in equality issues is generally about women, but I have a son who is 34 years old. My experience, struggle and campaign really began with him, very many years ago – 32 years ago – on the disability issue, because I wanted mainstream education for him then. They used to call me a lunatic. I do not think that nothing has changed since then, but I got very little justice for my son. Nonetheless I have retained an element of interest in this, and I was on the board of Autism Speaks, now Autistica, for about five years. In fact, with them and in my own interest I have looked at quite a lot of the disability provisions in different Muslim countries. I am very impressed with some of them. I was very interested in the issue of the perception of disability and how it impacts families. Very often, my son used to be called mad, and it is the one thing he still says. Nobody is allowed to say in front of him, 'I'm mad'. You know, I cannot say, 'I'm mad' as in 'angry', because he will still instantly say, 'I'm not mad'. That really hounded him for a long time. Anyway, I am deeply interested in this issue, and thank you for the opportunity for allowing me to participate.

**Heather Wheeler MP**

It is a pleasure. The beauty of this inquiry is that it is absolutely all-party. I am going to be chairing this first session, and other sessions will be chaired by Anne McGuire and Baroness Campbell, who are the co-chairs of the Disability APPG. What we are really trying to tease out, and what we hope we will find finally in the report that we will be able to send to ministers, is evidence today that will contribute towards the final summary, which will contain recommendations about how to reform social care for working age disabled people. We are really looking forward to hearing your evidence today. Thank you very much indeed. Tom, would you like to kick off with the first question?

**Tom Clarke MP**

Madame Chair, can I apologise again to you and to the ladies who are here? I have to leave for another committee at 2.30, but I am delighted to see you. I would like to put this double-barrelled

question to you. In your experience, would you say that the social care system is failing to support disabled people to live independently? How can any social care reform best ensure that disabled people can enjoy their right to independent living?

### **Liz Sayce**

First of all, for many people, yes, it is failing. I really welcome this inquiry, and I am really pleased that the first question is about independent living. We would like to see the purpose of social care as being, as the Equality and Human Rights Commission put it, a springboard, not a safety net. It should enable you to live the life and participate fully in your community and your family, not just make sure you are fed, to put it at a basic level. The reason I say it is in many ways failing is that firstly, we have some statistical data that suggests there is a real difference between disabled people and non-disabled people in terms of how much choice and control people have in day-to-day life. That is from the Office for Disability Issues, and I can send it later on. They pulled together lots and lots of data, and it was very useful. Secondly, regarding day-to-day experience, we had an event in Manchester yesterday, and a young man who wanted to move out of living with his parents was told he could only move into sheltered accommodation. He had a direct payment, so he had choice and control, and he had a personal assistant. He was told that to move away from your parents you have to lose your personal assistant, you cannot have a direct payment, and you will get the staff in the sheltered accommodation, whatever it is. That is just one small example.

We have seen really good research led by disabled people on things like the experience of people with spinal injuries being in residential care, and that is not where they want to be, because there is not the support outside residential care. People are saying things like, 'I feel like a prisoner, not because of my impairments but because I am not able to even get up when I want to'. I think there are massive variations between different local authorities in terms of the extent to which people get self-directed support, and to what extent people get direct payment. Some people are having a really good experience; perhaps it is important to say that it is not a failure for everyone. However, the disparity is absolutely enormous. So I think one of the things that needs to happen going forward, to answer the second bit of your question, is a stronger legislative framework around independent living. We could debate that, but one way would be to put an obligation of duty on local authorities to ensure that there are particular independent living outcomes around things like participation in the community and employment, and so on. It does not mean that every place has to do it the same, but at the moment it is too variable, and some people are desperately isolated. Some people are going into residential care against their wishes, and some people are desperately isolated at home. Eligibility criteria get ever more stringent, and you do not see those crises so much because people are at home, not able to go out at all, but that is a major unseen crisis.

### **Heather Wheeler MP**

Jane, I wonder if you would like to come in on that point.

### **Jane Young**

I can do. I would totally echo all that Liz has said, and I think the very sad thing about a lot of what she has said is that it was back in the 1970s that disabled people were fighting to get out of the imprisonment of residential care. What we are starting to see now, I believe – and because I do not deal with loads of statistics I can only say anecdotally – is history going backwards, or regression. We are having regression. I think the main reason for regression is lack of money, but along with

lack of money, all sorts of other things have started to happen. From what I hear from disabled people around the country, I do not see social care staff having any aspiration for those they support. Their aspiration seems to be a feed, clean and leaving incontinence pads aspiration, which is no aspiration at all for disabled people. It is utterly disgraceful. However, of course you can understand that they do not have an aspiration.

This is an anecdote that I think is appalling. I have a friend who is younger than me. She is 37 and she lives in the Wirral, which has apparently long had a bad, bad reputation for social care services. The social care worker who assessed her had decided that she needed various things; she needs a significant amount of help. It went to panel, and panels are a huge issue that might be worth having a look at. Panels are there to ration and save money. They cause delay because every proposed package has to go through panel. Neither the service user nor their advocate is allowed to present a case to panel. Nobody knows who sits on them. Their decisions come down without justification or reasoning, and the way they operate appears to fly in the face of common law and natural justice. When this proposed plan went to panel, they were trying to take everything out of it. They seemed to ignore the fact she is 37 and wants a life. The first thing they said is: ‘Why can’t she have meals on wheels rather than assistants to prepare food?’ She has to have a gluten free diet, but 37, meals on wheels? It just felt so wrong. Why can she not be assessed for NHS continuing care? She is not likely to be eligible, but this is yet another way to try to get this problem out of our budget and stick it on to somebody else’s. She is completely traumatised because she knows she needs help, and she just does not know whether she can manage to fight it. She is not sure whether her mental health can cope with fighting it. I will put the full thing into my written evidence.

### **Heather Wheeler MP**

Yes, please.

### **Jane Young**

Another huge issue around under-funding, lack of aspiration and panels is that personally, I do not think that personalisation has produced independent living. I think there is a huge danger in thinking that personalisation is going to achieve everything, because you can have a personalised service that does not actually achieve independent living. By focusing on personalisation, personal budgets and resource allocation systems, much of that is about trying to ration, and the aspiration for independent living has got lost somewhere. So in terms of what I would do differently, I would definitely go for a system that provides the same broad level of support and eligibility regardless of postcode. It cannot be just that if you live in the Wirral, you are fighting for every little thing, but if you are living in some other places – it used to be in Kingston, but not quite so much now – you get something decent. I do not think portability is properly addressed, so I think people should be able to take their package, and the money should go with the person to the new area. I think service users should be allowed to keep a much more reasonable level of income and capital after their charges have been taken off, if they have to be charged as working age. As Liz says, the aspiration needs to be about equality, and people having the same independence, freedom and ability to participate as their non-disabled peers. I think residential care should be the very, very last resort, but only if it is what the disabled person actually wants.

### **Heather Wheeler MP**

Jane, that is very clear. Thank you. Julie?

**Julie Jaye Charles**

Is the social care system failing disabled people? We have recently done a report with Scope, which is called *Overlooked Communities, Overdue Change* and this report was debated in the House of Lords on January 10. The outcome of the report was that there were many BME disabled people up and down the country that felt that the social care system did not understand them, did not understand what their needs were, and they were having huge difficulty in accessing the system, because the system itself is actually set up to fail a lot of BME disabled people that experience multiple barriers to service provision. One of those barriers is the fair access to care criteria. Lots of local authorities now have got substantial and critical levels, and many disabled people fall into lots of different brackets, but that does not mean that they should not have a holistic package of care and support. How can disabled people enjoy a right to independent living? I think that again, there needs to be a holistic way of delivering personalisation, which cuts across health, social care and housing, because a lot of disabled people from our communities actually use community advocates. I have a mixture of advocates that work for me, and also social workers and trainee social workers. What we are finding more and more is that people want to self-assess their own needs. When we go to panels to support individuals to get a care package, there are many un-met needs. We record that un-met need, and a lot of it is down to a lack of cultural understanding.

**Heather Wheeler MP**

Fascinating. Thank you very much. David, would you like to ask the second question?

**David Ward MP**

Some of the issues are the postcode lottery and the minimum entitlements, and these will be covered in the second session, in which we will be looking at eligibility criteria and so on, including the FACS criteria no doubt. I am very interested in the comments you made on the culture of aspiration. The business end of this should be recommendations. What we would like to do at the end of this is to recommend things. So when you are answering, if you can think in terms of what we should be doing, in your view, and what are the things that will make this thing better. The area I would like to look at is the social care reforms that are going through. In terms of specific recommendations to ensure that disabled people can enjoy their right to independent living, what are the things that need to change?

**Liz Sayce**

I would like to see duties on local authorities framed in human rights terms, and in terms of independent living. However, the duty is about enabling outcomes: independent living outcomes. I do not think you can say exactly what service you should be entitled to, because it will not be the same in a rural area and in a city. Therefore, rather than going down that service entitlement route, I think that local authorities should be held to account for the outcomes in areas like education, employment, and social relationships. This would capture the point I was making earlier about isolation. Local authorities should be monitoring outcomes such as the family life and social networks of disabled people who are receiving either direct payments or social care support. There is also the issue of positive health. I am extremely worried – just to drop in one other real concern – about what is happening in mental health around the huge growth in people being compulsorily detained and also subjected to compulsory treatment in the community. I do not know if you know the figures, but the graph is like this. It just goes up and up every year.

I have had mental health problems, and I come from a mental health background. People say that to get a service you almost have to have one foot off the bridge; that is the kind of thing people say. What is happening in a way is that people are not getting support when they ask for it, but then they are getting compulsory treatment from the health system further down the line. This is another outcome that I think we should track, and it varies by different impairment. Young people with spinal injuries are ending up in residential care when they do not want to be. People with mental health conditions want support do not get it, and then end up sectioned.

I think that local authorities working with partners need to be held to account for good health. We would measure it in ways that include looking at whether people are going into residential establishments against their will or being detained against their will. I know that is not terribly specific. In terms of a mechanism, we would like to see an extension of the right to control, whereby individuals can bring together different funding streams. For example, you might be managing your own PAs both at home and at work. If that is the case and you are getting some money from Access to Work and some money from social care, it may make more sense for you to be able to do that seamlessly and integrate what you need. I think the mechanisms need to be changed, and they need to be far less bureaucratic than they are at the moment. There is at least one local authority that has managed to plough money into direct service provision and support simply by not monitoring so often. As somebody who is always filling in those endless forms for Access to Work returns, in some cases, there is a bit too much emphasis on monitoring. It is understandable, because you have to have accountability, but it could be much more light touch. The money should be going into the direct support that people want and need.

### **Heather Wheeler MP**

That is very helpful. Julie, would like you to come in before Jane on this one?

### **Julie Jaye Charles**

Yes. I would like to see a lot more recognition of the support and the partnerships that the voluntary sector and the third sector could have with the statutory sector in providing services. I would like to see a statutory duty implemented for advocacy, because disabled people often use advocates, and need advocates to actually support them to speak up for themselves. I know disabled people from our communities often request to have an advocate, and I would like to see that put into the bill as a right, so that an advocate can be there during any discussions about a person's care and support. I think that the bill is currently missing the trick when it comes to personalisation and independent living, because it is not looking at working age disabled adults. It is more around adults over the age of 65, and that concerns me, because the thousands of disabled people actually have impairments during working age, and they need the same support. So I would like to see changes of the bill around advocacy, and a more holistic approach to providing services.

### **Heather Wheeler MP**

That is great. Thank you very much, Julie. Jane, do you have some other thoughts?

### **Jane Young**

Yes, I think that there is an awful lot involved in supporting disabled adults, especially those with high care needs, to live independently. I am very concerned that the support provided through the

Independent Living Fund must be protected if that fund is closed; we hope it is not, but it will probably be. The aspiration around the Independent Living Fund and the funding that provides is very much more appropriate than the lack of aspiration I have spoken about in social care services. In terms of the bill, I have already mentioned that I do not think the portability goes far enough. I think the money should follow the individual. Social care staff need to have a focus on both independent living and equality of opportunity, and I think they need to focus on equality of opportunity for people with their non-disabled peers. If the support package and other services are not providing that equality of opportunity, then that is not sufficient. There are dangers around the way carers' needs have been addressed in the bill. I think they are good, but there should be a very clear lack of expectation that a family member will provide care unless he or she wants to, and the disabled person wants that. There is a lot of reliance on informal support that skews and causes lack of balance within family relationships, so disabled people need to be able to participate in personal and family relationships in an equal way as far as possible, like their non-disabled peers. I think our care system and support system are a long, long way away from that being a reality. I also think that independent living will not be achieved unless the public services and regulation work together. Without an accessible transport system and strong anti-discrimination legislation that actually works for employers, social care can try all it likes, but it is not, on its own, going to be able to provide independent living and equality of opportunity.

### **Heather Wheeler MP**

That is very interesting, thank you. Sarah, would you like to ask a question?

### **Sarah Newton MP**

Yes, I am going to go a bit off-piste, Chairman, and respond to something that Liz said. Obviously this bill creates the health and well-being boards, and I really like what you were saying about focusing on outcomes. Rather than prescribing – people should have  $x$  hours of this, or they should be entitled to a certain type of service – it is really about their outcomes, so I think that is absolutely the right way to go. Can you see any reason why the health and wellbeing boards could not be given that responsibility? They have been created by the Health and Social Care Bill, and the whole direction of travel is for the Government to integrate those services. So alongside other outcomes like reducing cardiovascular disease, and all the things that the health and wellbeing boards are going to have, could they not have outcomes for working aged people living with disabilities?

### **Liz Sayce**

I think that is positive, and it would be useful to have that kind of multi-agency approach to the outcomes, because obviously there will be different strands that need to come together to enable someone, for example, to sustain employment. The only caveat is that I think it is really important that the organisations that do hold the budget for social care specifically do have accountability within that system. As I said before, I think at the moment the disparity from one part of the country to another is too great. Whilst you obviously want some sensitivity to genuinely local requirements and needs, I do not think that is what all that disparity is about. I suppose one of my concerns, alongside the concern about people with the most complex needs, is about people who would be viewed as having moderate needs. Once there is the change from Disability Living Allowance to Personal Independence Payment, they are the people who will lose that income to cover the extra cost of disability. At the same time, if there is a local authority that has only got eligibility for people in substantial and critical need, they will not get that either. To paint a picture,

for example, this could be somebody with a learning disability who, with a bit of support, could be going out, engaging in activities, travelling and doing things. However, without that support they just will not be able to do anything. It might not be a total crisis, but it is going to be very bad for their wellbeing. I suppose that you could give the responsibility to the health and wellbeing board, but I would want to see some discrete responsibilities within that, so that it did not become a case of, 'It's everybody's responsibility and no one's'. That would be the only thing.

### **Sarah Newton MP**

I can see the point you are making, but the health and wellbeing boards are clearly the responsibility of the first tier local authority, and it is the first tier local authority that have the responsibility for social care. The health and wellbeing boards have the Director of Social Care as one of the board members alongside housing, the voluntary sector, all the patient groups, advocate groups, and all the parts of the NHS. That is where everybody comes together in a locality to share responsibility collectively for health and wellbeing for their community. Each of them then has their own discrete responsibility. Now, we are coming on to eligibility criteria in another session, so we are assuming that the Health and Social Care Bill does tackle the eligibility criteria adequately for people living with disabilities. So that eligibility criteria is established, and then it is a question of who is going to be accountable for delivering the services to enable that to happen. I would be interested to know what you think. If it is not the health and wellbeing board, who is it that is going to be responsible? Would you see it as just the responsibility of the council through the adult social care services? Is that how you would see it going, rather than through the wellbeing board?

### **Liz Sayce**

Perhaps I will start. I think that for the piece that is specifically about social care, there needs to be accountability of the local authority. However, as you say, I think it would be fine for the health and wellbeing board to have that responsibility for the wellbeing of adults living with disability in that area. I am just conscious that the health and wellbeing boards have got an absolutely massive agenda. That is the only reason I am giving this caveat, and we would not want this to get lost.

### **Sarah Newton MP**

I am going back on-piste, in terms of what I am supposed to be asking you about. I am particularly interested in that group that you identified, of people who actually want to work; if they had co-ordinated services to support them they could work, and could then play a much larger role in the community for the benefit of themselves, and in fact everybody else. That is the group that I would like to ask about. Have you got examples – both good and bad – where people have had packages of care that have enabled people to work, or where it has not worked, and they have been let down by social care? I would like to know about the consequences: what that has meant for those individuals or groups of people, or any reports that you can point us to, so that we can include that evidence in our inquiry.

### **Julie Jaye Charles**

We are working with the DWP on supporting disabled people from BME communities with the Access to Work programme, and it has been successful. What is failing a little bit is where someone has a direct payment for their social care needs. What has happened for a few people – this is in *Stop, Look and Listen* – is that their direct payments have been cut because they are going

back to employment, but their social care needs still remain while they are in employment. Someone has got a personal assistant, for instance. That personal assistant is not just for personal care. It is also around social mobility; it is typing for an individual, or whatever it is. I have heard of people having that side of things taken away from them, or the hours broken down. However, individuals really do want to get back to work. In particular, we are working with some ex-offenders with mental health difficulties, and the programme is working very well for them, but they are individuals that have not met the FACS criteria for other forms of social care and support, although they have met the criteria for Access to Work. I cannot knock Access to Work; it is doing well for the individuals that we are working with, and there have been positive outcomes.

### **Sarah Newton MP**

It is my understanding – but correct me if I am wrong, because you are bound to know more about this than me – that under universal credit, people living with disabilities can now earn up to £7,000 without any of their benefit withdrawn, so surely that is going to help what you are talking about? I clearly understand that we do not want to disincentivise people once they start to earn. It starts to have the cliff-edge effect of taking away valuable services like social care, which enabled them to work them in the first place. That is my understanding of what is going to happen in universal credit. If that is the case, if I am right, is that going to ameliorate that situation?

### **Julie Jaye Charles**

Yes, it would, but nobody knows enough about universal credit right now. I know through my team that they are just beginning to get training on it, and with the whole PIP process all the benefits are all coming into one. However, I think that if it is going to allow disabled people to have greater opportunities, then so be it, because that is what we need for individuals.

### **Heather Wheeler MP**

I was almost going to finish the session there, but I will not, because that would be naughty. No, I am joking, Baroness Eaton. Don't worry. Jane, would you like to tell us your thoughts on this one?

### **Jane Young**

Can you just remind me of exactly what I am going to be focusing on?

### **Heather Wheeler MP**

Employment opportunities.

### **Sarah Newton MP**

Yes, employment opportunities. If there are any barriers that you have seen, or good examples of social care working, which is enabling people to work?

**Jane Young**

I think that very close co-operation between Access to Work and social care services is really important. I know some good examples of people, and one of them sitting in this room is the example I usually use, so that is slightly embarrassing. If that support is seamless and the support for helping with emails at home – after you done all the getting up and getting ready bit – and driving to work, that could be social care or Access to Work. People do not fit into little boxes. For a lot of disabled people, especially people with fluctuating conditions, the kind of work they can do is quite limited, but there is nothing wrong with their ability to think. Working at home: we are always being told about how flexible work is, but in many ways it still is not. Many employers are still not flexible. I think that both DWP staff and social care staff have got to be a lot more in tune with what actually works for disabled people, if they are to be economically productive, and if they are to earn and pay taxes. As I said before, there is a big problem with social care services not getting anywhere near the aspiration of the level of independence, particularly for severely disabled people, which would even make work anything that you could even contemplate. Furthermore, there has to be a much bigger focus, both locally and nationally, on the needs of working age disabled adults and what they really need, rather than being lumped in the pot of ‘frail elderly people’, because our needs are very, very different. What we expect to be able to do, as younger adults, is very, very different, and I guess it just comes back to what I said before. I think one of the outcomes has got to be looking at equality of opportunity; what that means for that person and, as far as possible, within the bounds of their impairment.

**Heather Wheeler MP**

We have been joined by Baroness Eaton. I am delighted that you can come.

**Baroness Eaton**

I am so sorry I was late.

**Heather Wheeler MP**

Not at all. Julie, did you want to come back?

**Julie Jaye Charles**

Yes. I just wanted to come back on the health and wellbeing boards, and open that up around Healthwatch. I am a little concerned, given the responsibility to the health and wellbeing boards, because unless they have disabled people actually being represented on those boards, I think there is a possibility that they are going to miss the trick, and focus solely on the health side. It is great if we can bring health and social care together, but if we are talking about health and wellbeing, a lot of people on the boards, and particularly GPs, may just focus on the medical side of things, and look at people as having ailments that need to be cured, instead of looking at what could be put in place in order for someone to live independently.

**Heather Wheeler MP**

Baroness Eaton, do you want to join us?

**Baroness Eaton**

Thank you. Yes, I am so sorry I was late and missed your earlier contribution. I will catch up and read what was said. You have talked quite a lot about your concerns about the separation from health and social care. I think for any of the thinking that is being developed around the Health and Social Care Bill there is a real need for the two to be really integrated. I really would be interested to know what you think those barriers are, whether it is deep-seated, and what challenges we could present to bring things together, or whether there are more simple solutions that would make it work.

**Heather Wheeler MP**

That is lovely; believe it or not, you are a mind-reader, because that was pretty much going to be my question.

**Baroness Eaton**

I am sorry.

**Heather Wheeler MP**

Not at all. That is lovely.

**Baroness Eaton**

I am going to have another very small one.

**Jane Young**

I am actually going to be rather controversial.

**Baroness Eaton**

Please be.

**Jane Young**

I am really not convinced that the major issue for working age adults is bringing together health and social care.

**Heather Wheeler MP**

That is interesting.

**Jane Young**

I am much more convinced that we should at least look at the idea of bringing housing and social care much closer together. We have just been talking about people in employment. A few months ago I heard of a young lass who had been offered an internship at the Department of Health, but she could not find anywhere accessible to live, so she could not come. The Department of Health were waiting for her, but she could not come. I have a friend in Southampton, and sadly she is not able

to work any more, but she was a rising star in the academic world. She was offered a prestigious appointment in Newcastle, which would have been fabulous for her career. She could not get social care sorted out in Newcastle, and was not able to go. At the time, she was one of the leading up-and-coming mathematicians in the world, I believe, and she was not able to go. Housing is essential. If we are talking about increasing independence, and reducing the cost of providing services that do not quite work, then housing, housing adaptation and building new homes that at least are lifetime homes is important. The developers might moan, but sorry, it is not that expensive. All lifetime homes, 10% wheelchair standard, but not just in the social sector.

There has got to be the housing, and if you are in the housing, there has got to be the adaptation. Disabled people who are in private rented accommodation sometimes need a lot more support from a PA, for instance, because you cannot get adaptations in the private sector. What private landlord is going to want to put in significant adaptations? I think that in terms of getting a mix that will start to reduce the costs and improve the quality of life, there is a strong case for housing and social care to go hand in hand. Not that I think that market housing is dealt with in that sense by the council. However, if disabled facilities grants are done properly, and if the adaptations are done well, they can improve quality of life and reduce the need for support. On the basis that a lot of disabled people are disabled and not ill, then I actually think there are huge dangers going with health, because then social care could go back to this thing of being looked after. It is not; it is being supported and empowered.

### **Heather Wheeler MP**

I am very acutely aware that we are finishing at three o'clock. There are quite a few questions left. Can Baroness Uddin do hers, and then please come back in after that, Margaret?

### **Baroness Uddin**

Thank you. I was holding on to my seat as I was hearing some of what you had to say. In some ways we have come so far and there are so many amazing champions, particularly in this place. Mindful of that, I just want to get to the point that I really want to know. You have been talking about wellbeing, and I want to veer off the question to a particular point that I want to make, which comes from the *Overlooked Communities* report. I have two questions. Why do you think some of the mainstream disability organisations are finding it so difficult to reach out to the overlooked communities, particularly the minority communities? The second question is: what is your analysis of the fact that there are very, very few disabled individuals going for direct payment or personalisation in that sense from our communities? I am particularly concerned about those two issues, in the light of the emphasis that we have all put on choice and control. There are lots and lots of things that I would like to bring into that, including having a healthier life and a personal life. For instance, there have been quite a lot of aggressive newspaper articles and publicity around marriages within our communities of disabled people, whereas there is quite a lot of encouragement about having girlfriends. That is perfectly all right, but there have been issues with parents and marriages, and a number of them have ended up in care as a result, or they have ended up in the dock. I am sorry that I have shared with you a little bit more than I wanted to, with regards to the questions, but I would love to hear some feedback.

**Julie Jaye Charles**

The lack of BME disabled people in mainstream disability organisations is a huge concern for us at the Equalities National Council. We have tried to work with a number of mainstream white-led disabled people organisations. I work very closely with Liz, and we work extremely well. I also work very closely with Scope, and that works extremely well too. However, there are other bigger charities that do find it difficult to reach out to BME disabled people. I do not have the answer, but what BME disabled people do say in the *Overlooked Communities* report is that they experience a lot of multiple discrimination on the grounds of their race and their disability. I should add, though, that it is not only the white-led disabled people organisations. A lot of the black-led race organisations also have a problem with disability.

**Baroness Uddin**

Sadly still led by men.

**Julie Jaye Charles**

Yes, absolutely, and I think it is important that that is said.

**Baroness Uddin**

Good men.

**Julie Jaye Charles**

Can you remind me of the second part of your question?

**Baroness Uddin**

I was talking about choice and control.

**Julie Jaye Charles**

And direct payments?

**Baroness Uddin**

Why there are not more people.

**Julie Jaye Charles**

It is one of these things where a lot of communities are so used to just looking after their own, being forced to look after their own. A lot of people do not have the information, and are not told about what direct payments and individual budgets are. It is more than likely that most of our community will not even know that there is a health and wellbeing board being set up in their area, or that Healthwatch is coming into play. For something like a direct payment, that is a big deal. Now, when my advocates and social workers work with individuals, we always look at the most holistic

way of providing a service. Part of that is seeing if people feel that they would like to go through the process of getting a direct payment. Again, like I said earlier, the FACS criteria often let people down, and they do not get it, so there is an issue there.

### **Heather Wheeler MP**

Thank you very much indeed. I am going to press on, because Rosalie has got a question that she is itching to get in.

### **Baroness Wilkins**

ILF is in the news today. What do you think will be the effect of the closure of the ILF on the commitments that our country has made under the UN Convention, Article 19? Specifically it states that disabled people have a right to live in the community with the support they need and can make choices like other people do. So what is the effect of the closure of the ILF potentially? Shall I start with you, Jane?

### **Jane Young**

I will be brief. I think if the aspirational ethos behind the ILF and the money is not put across into social care services and possibly ring-fenced the way that it should be, the problem is that for disabled people who for many years have been very active, with maybe a 24/7 support package, employing PAs, doing paid work, being part of the community, and all the rest of it, the shock will just be huge. There are some brilliant videos on the Disabled People Against Cuts website at the moment; there are videos and written testimony from current users of the ILF, which probably says a lot more than I could say. However, I think that if you inflict on those people the poverty of aspiration and the lack of funding that you get going for social care from a local authority, then the outcome will be tragic for those 19,000 people, or however many it is. Not enough money and not enough aspiration is a huge danger, unless that is properly addressed.

### **Baroness Wilkins**

Can I just follow up that, Jane? Do you think that you can transfer that aspiration to social care?

### **Jane Young**

I do not think so.

### **Baroness Wilkins**

Would it need to be an independent organisation?

### **Jane Young**

Even if you were able to inculcate that level of aspiration within adult social care services – 152 adult social care departments around the country – it would be of little effect if there was not the funding to go with it. That goes back to my friend in the Wirral. The person who assessed her had plenty of aspiration; the panel had none.

**Baroness Wilkins**

How important is it that that funding is separate from the whole social care fund?

**Jane Young**

I think it really needs to be looked at. There will be severely disabled people who need that, who are not part of the ILF. It is all about having the funding to make sure that this equality of opportunity aspiration and independence aspiration can be realised, and is not just an aspiration that becomes a reality. You cannot get away from the fact that it costs money to support us. However, my view is that we contribute hugely if you do it.

**Heather Wheeler MP**

That is a super way to end, and I will leave it there. George has got the last question, and you may be able to weave something into George's question.

**George Hollingbery MP**

I was going to ask you an open question. I have actually got a particular question to ask, but I think the nub of it is this: if we make recommendations in this report that are just about money, we are probably not going to get very far. I think you know that perfectly well. How much of what needs to be done is about money, and how much can be achieved by aspiration, by doing things differently, and by looking at things in a different way? That is my opening question. The particular question that I would like you to comment on is about portability, and how much that will help. Jane, I think you have already referred to it fairly extensively. Do you see any difficulties with the way these provisions are actually designed to work within the bill?

**Liz Sayce**

Firstly, there is clearly a need for a decent funding settlement. I also think that at the moment, money is spent on services that lack aspiration, and we could do better with the money we have got. If I could give a couple of examples, going back to the employment question. I recently visited a service where a lot of people with learning disabilities were all out at work during the week, and they came together on a Saturday. Social care had funded a voluntary sector organisation for the peer support between people with learning disabilities in employment to support each other, and get the support they needed to be in employment. This was instead of what was happening before, which was running a day centre every day of the week. You know, you can do that, but I have to say that not every social services department is operating like that. Some are supporting organisations led by disabled people to have a complete cultural shift. There are models, and we could support them. At Disability Rights UK we have done one recently, which is about peer support around employment and developing your career, which has just been identified as an international example of good practice. I could share it; it was relevant to the earlier question from Sarah. I do think it would be good to make some recommendations that are about transformation, which are not only about money, but we need a decent financial settlement. On portability, it is not enough just to be able to take your assessment from place to place. It does not have to be exactly the same provision, because it might be that service configuration is very different in the area that you go to. The important point is the commitment to you achieving those outcomes. If you want

support to go to work, or whatever it is, then that should be replicated in the new place, and you should have the resources to do it.

**Heather Wheeler MP**

Julie, a final thought from you, please?

**Julie Jaye Charles**

I totally agree with Liz, 100%. It is not all about money. Just like Liz said, there are things that can be done differently. People have a right to independent living. They have got a right to choice, they have got a right to control, and somewhere along the line, yes, money is going to be a question, and it will also be an answer to people's dreams, but it is not the be all and end all. The majority of people want freedom. They do not want to be locked away in institutions that cost the Government loads of money. People would be very happy to have a budget allocated to them looks after both their health and wellbeing, which does not need to cost the earth.

**Heather Wheeler MP**

Jane, last point?

**Jane Young**

I have a very quick point in terms of not spending money. At the moment we have 152 social care departments around the country, all of which consult on and create their own charging policy. Now, to me, that is 151 too many. Why on earth? If we did some of this stuff that only has to be done once, once, we could save all that time. Obviously you would still have to assess people, but at least you would not have to construct a different policy for every area. We could say it was similar for eligibility criteria. I think there is a hell of a lot of duplication that goes on around the country. We are only a small country.

**Heather Wheeler MP**

Ladies and gentlemen, thank you very much indeed. I will close the session now. I am really grateful for you coming along, and I am sure you will enjoy reading the report when it finally gets done. We will see you again, hopefully at the launch if not before.

## **The Impact of Changes to Eligibility**

### **Members:**

*Baroness Campbell (Chair)*

*Lord Tope*

*Sarah Newton MP*

*Baroness Wilkins*

*George Hollingbery MP*

*Baroness Uddin*

*David Ward MP*

*Baroness Eaton*

*Tom Clarke MP*

*Lord Low*

### **Witnesses:**

*Richard Humphries, Senior Fellow, The King's Fund*

*Dr Marc Bush, Head of Policy and Research, Scope*

*Andrea Sutcliffe, CEO, Social Care Institute for Excellence*

### **Baroness Campbell**

I call this session to a start. Firstly, let me welcome you. Thank you very much for coming today. We are not here not going to grill you; we are here to learn from you. Whatever question you want to ask, please feel free to expand. I would like to welcome Andrea Sutcliffe, from the Social Care Institute for Excellence; the organisation, of course, which I love best in the world, being the valued chair. Richard Humphries, from the King's Fund, another organisation that I have had a long association with. Thank you for coming. Dr Marc Bush from Scope. We are very much looking forward to hearing about your insights into the eligibility criteria, and its effects on disabled people in this country. Before we start, I would like to introduce you to the panel, and I will start with Baroness Eaton.

### **Baroness Eaton**

I am Baroness Eaton, and I am a Conservative peer in the House of Lords.

### **Sarah Newton MP**

I am Sarah Newton, Member of Parliament for Truro and Falmouth.

### **Lord Tope**

Graham Tope, Liberal Democrat in the House of Lords.

**Baroness Uddin**

Pola Manzila Uddin, House of Lords member.

**Baroness Campbell**

Baroness Campbell, independent cross-bencher.

**Baroness Wilkins**

Rosalie Wilkins, Labour peer.

**David Ward MP**

I am David Ward, Member of Parliament for Bradford East, and a Liberal Democrat.

**Lord Low**

I am Colin Low, and I am a cross-bench peer in the House of Lords.

**Baroness Campbell**

We have a couple of panel members, Tom Clarke and George Hollingbery, who are in and out of voting; they will be with us at some point. We are due to finish at half past five, and we will aim to be on time. Shall I kick off? Let us start with something easy. I guess to start, just one or two sentences about what you consider to be the greatest weaknesses of social care eligibility criteria for the participation of disabled people as active citizens in this country. We will start with Andrea.

**Andrea Sutcliffe**

You just bowled me a nice easy one there, thank you very much. I think that perhaps I would say one of the greatest weaknesses, and particularly thinking about your inquiry, which is around the impact on disabled people of working age, is that if you look at the people who are using social care and support services, the vast majority of those are older people. Quite a lot of the approach and the development has actually been swayed by doing the greatest good for the greatest number, therefore concentrating on some of the issues that would be very, very pertinent to older people. What that means in terms of a weakness for working age disabled adults is not necessarily a concentration or a value, if you like, placed on the aspirations and the needs of people of working age, particularly around wanting to have employment and those kinds of things. If you are looking at eligibility criteria focused on basic social care needs, then we may be missing a trick around the support that we could more appropriately provide for people who do wish to live independent lives and contribute, as we know they can do, to the world of work.

**Richard Humphries**

I agree with much of that. It seems to me that the main weakness of eligibility criteria in their current form is that they have outlived their usefulness. We have a position now where 85% of local authorities are operating at areas of need that are at least substantial. These criteria were originally introduced to encourage councils to be more consistent in the responses that they gave to

people's needs. Back in 2005, for example, over half of councils were responding to much lower levels of need. That has changed, so they are all up there at the moment with a very, very high level of eligibility. Their original purpose has really been taken over by the extent to which those criteria have been ratcheted up. I like to describe the criteria as a zombie policy of adult social care, because it is kind of limping on, neither alive nor dead, and it really now has very little impact on the kind of service that people get. You can look at local authorities and see massive variation in the help that they get, irrespective of the level of eligibility that a council is operating at. So we see, for example, a tenfold variation in access to direct payments. We see a sevenfold variation in local authorities in access to intensive home care, so eligibility criteria is kind of an answer to yesterday's question, I suppose. As Andrea has indicated, I think in conclusion that we need to be much clearer about what it is that we are assessing eligibility for. Is it for a very narrow range of traditional, professionally-driven services, or do we need to look at a completely different model? I will pause there.

### **Baroness Campbell**

Marc, do you have anything to add to that?

### **Dr Marc Bush**

I think Andrea and Richard have said quite a lot there. Perhaps I will just draw attention to three points, which I am sure we will talk about in more depth. The current eligibility criteria based on fair access to care services is out of date. I think it is probably out of date for three big reasons, in addition, and it is partly the same as what Richard said. The first one is that it is based on a risk model. It is not looking at outcomes for individuals, but the risk that is posed if they do not get care and support. The second one is that local authorities have discretion as to how they apply eligibility, meaning that there is massive variation across the country. I think thirdly, there is a massive variation in interpretation by people working in local authorities. Although there is guidance in a very positive way, some frontline professionals want to make sure that it is the greatest number of people who are contained within the formal care system, and therefore massage, to some extent, the eligibility criteria. What I would like to finally say is that we have done a large piece of work, along with four other disability charities, talking to disabled people about what they want out of the social care system. They were saying that first and foremost, the issue they are most concerned about is whether or not they get care, and if they are seen as part of the formal care system or they fall outside of it, and are left to families or no support. They told us that the most important thing is eligibility, because it is whether they are recognised as being part of that formal care system or not.

### **Baroness Campbell**

Thank you very much. Now, as Sarah Newton rightly reminded us, we are very much looking through the prism of the forthcoming Care and Support Bill, so bear that in mind when you give your answers. Baroness Eaton?

### **Baroness Eaton**

Thank you. Yes, I was fortunate to be on the Committee that has just looked at the Care and Support Bill, and a great deal of our time – well, not a great deal, but a considerable amount – went

into looking at portability. I just wondered if you think the current portability provisions in the bill will help solve the problem.

**Dr Marc Bush**

I am happy to go first. I think the current bill, as it is drafted, does increase some of the co-operation between local authorities boards, so local authorities and health services, which is really positive. It is a positive step forwards. I think there are probably two things missing, which could usefully be added in. The first thing is that there is nothing about the equivalency of a service. Currently, if you are in one area and you move to another area, you might have a new assessment. They might be co-operating well with that original authority you came from, but your new service does not have to be equivalent to that of the one you left. I am not saying that the bill should specify you have exactly the same services, because that would be silly. Each area needs the provision that works for that individual, but you want something that guarantees the person will have the same outcomes, and therefore the service being provided gives equivalent outcomes to the ones the person was getting, or improved outcomes.

**Baroness Eaton**

Can I just come back on that? I think that what you said at the end actually helped, because you gave the impression that the package should be the same, and of course, the reason the person moved might be because the facilities where they were would demand less service. However, what you do say is that the outcome should be the same.

**Dr Marc Bush**

Yes, it should be balanced off, and making sure that we are guaranteeing at least the outcomes they were experiencing in the previous authority, and then preferably promoting better outcomes.

**Baroness Eaton**

My understanding is that they move, and they have to have an assessment. There is a requirement, so it is not that they will not get one.

**Dr Marc Bush**

Exactly. The second minor addition that I think would help is that at the moment the new authority would not have to check what the care plan was for the existing one, and have regard to that in thinking about how the person would be supported. That is probably of vital importance, because care planning is quite a detailed process, hopefully and preferably. People go through and talk about the ambitions and outcomes they want, and think about the way that that could be met. As a starting block for thinking about how you are provided in a new area, you would want the old plan to be taken into account.

**Baroness Eaton**

Would it be in guidance, then, that follows the bill? It could be, couldn't it? That would be a way of covering that.

**Dr Marc Bush**

It could be, but it depends how it was drafted, because you want the decision to be made in regard to that, so it may need to be in the face of legislation. It depends on how that is written.

**Baroness Campbell**

Do either of you wish to expand upon that?

**Richard Humphries**

Just to add, if I may, I think the bill will help move things forward. It creates a much clearer understanding about what people can expect when they move. However, it will not achieve – and I do not think any piece of legislation can – this wicked issue that we have grappled with in relation to social care and indeed other public services, like the NHS. How do you get to a position where people get the service that they need on the basis of what they need rather than where they happen to live? It is the so-called postcode lottery.

**David Ward MP**

I think this is a crucial issue, because one of the selling points – amongst many others – that the Government tells us about the legislation is that it will end the postcode lottery, and what it is referring to is the eligibility criteria. There are concerns that it will be a levelling down in Bradford; we still have a moderate level.

**Baroness Eaton**

I hate to tell you, but it has just gone up. It has just been moved up to ‘substantial’ in the last week or so.

**David Ward MP**

There has been consultation on it, and they will change it. This was the way that they were going to remove the postcode lottery. What you seem to be saying is that even if the eligibility is levelled up, there is still likely to be a postcode lottery in terms of outcomes.

**Richard Humphries**

I am beginning to regret using the term ‘postcode lottery’.

**Baroness Uddin**

I think that what you are talking about is variation in services, and local demand and all of that. I think you have alluded, to some extent, to the answer to my question, but do you think that the setting of a national eligibility threshold will contribute to alleviating the problem of portability? I am also particularly interested, with regards to the *Overlooked Communities* report, about whether there has been enough done on educating the disabled community per se anyway, but in particular the marginalised communities.

**Andrea Sutcliffe**

I have two or three things to say. One is that there is a helpful element to setting a national eligibility criteria, but as Richard and Marc have already said, there are issues in terms of how that is interpreted corporately, if you like, by the local authority. There is also how it is interpreted on an individual basis, in terms of individual practitioners working through that with people who need to use services. So I think that yes, you can get legislation that sets a framework, and that is really helpful. However, what you have to back that up with is good guidance, but also good training to enable people to deliver on that in an appropriate way. The final element, to answer Baroness Uddin's question, is really about sharing information with groups who may be using services and their families and carers. What we know is that if people do have access to that information, if they are empowered by that information, know what they should be asking for, know what they should be expecting to have as an outcome, know that that service should be focused on their needs and them being able to contribute to that, and supporting that, then that is really important. What we have got to make sure is that one of the other provisions that is in the bill, which I am sure the committee looked at as well, is around information being provided locally; that we do ensure that that information is consistent, of high quality, reaches out to communities in a variety of different ways, and actually helps, as opposed to obfuscating. So I think we need to have some criteria around enabling us to assess that that is actually going to be the case.

**Baroness Campbell**

Thank you, Andrea. I am going to be quite ruthless on the questions, because we have a lot of questions. George, you wanted to ask quickly?

**George Hollingbery MP**

Just very briefly on that, Andrea, you used a word I was going to ask you about, 'outcomes'. Liz Sayce, who was one of our previous witnesses, said that this portability should be centred on outcomes rather than provision of service. Do you agree with that?

**Andrea Sutcliffe**

Absolutely. What we should be thinking about – and it is the whole personalisation perspective around the development and delivery of social care – is that it should be person-centred, and it should be based on the outcomes that are relevant to that individual. I think that that starts to get us into an area where we can be thinking about what people can do, what they want to do, and what they are capable of doing; not what their deficit is and what we need to do to kind of 'look after them', as it were, in inverted commas.

**Lord Low**

I would like to ask you a bit about the impact of the rising thresholds for social care. Andrea, I think you already alluded to this a bit in your opening answer, but I might ask you to amplify that a little bit. Before we get on to that, could you give us a bit more of a feel? It is all a bit abstract when we talk in terms of these categories: 'moderate', 'substantial' and 'critical'. Can you give us a bit more of a feel for who is actually included and who is not included as the criteria move up from 'moderate' to 'substantial'? Who is continuing to get social care under these raised thresholds, and who is falling by the wayside? Can you fill that in a bit?

**Andrea Sutcliffe**

I probably cannot give you it in absolute detail, and I apologise for that, but I think that what we are seeing is a concentration. The point that Marc was making earlier was about focusing on risk and the risk to an individual if a service is not provided. So what we are focusing on is: 'Is an individual going to be able to get out of bed in the morning and be able to feed himself or herself?' Therefore, for people who might be able to get a tick in that box, that is not going to move them into the 'substantial' or 'critical', but it would do if they were not able to do that. Again, I am afraid that is slightly abstract as well. Marc, I do not know whether your research around this would actually add a bit more life to it?

**Dr Marc Bush**

Maybe I can bring it to life a bit statistically and in terms of what people look like in that category. Currently 85% of councils have their eligibility level, which is called 'substantial'. That means that about 69,000 disabled people have fallen out of these formal social care systems at a moderate and low level in the last decade.

**Lord Low**

Does the research tell you anything about the kind of disabilities that they would have?

**Dr Marc Bush**

Yes. That 69,000 and the 36,000 that are still in the system with moderate level needs have a range of impairments, because eligibility is not based on an impairment type; it is based on a description of someone's risk to needs, as opposed to outcomes. It is anywhere from people with learning difficulties, who perhaps need some help around the house in terms of managing their finances or planning to travel. It might be people with autism who find it stressful going out of the house or socialising, or need some support in terms of the support worker going with them. It might be someone who has a hearing impairment that needs a whole range of adaptations both to their house and their social life, to make sure that they can interact with the world. Someone I was talking to has Down's syndrome and learning difficulties, finds it difficult to dress, but once they are dressed they can go around their daily business. It captures a wide range of people with a whole range of needs, both around personal, social care and communication needs, but also some people who need it for finance and socialisation.

**Lord Low**

This is to all three of you: can you say anything about the impact of rising thresholds on people's quality of life, on people's ability to live independently, for example, or to gain employment?

**Dr Marc Bush**

We did a large survey of working age disabled people across England to ask them about that, and the findings were really shocking. I am going to tell you a couple of stories. We were talking to a gentleman who used to get what was quite low level support to be able to get dressed in the morning, and then he would go about his day. As a consequence of not getting what was quite cheap, low level support, because the criteria and his authority moved, it meant that he could not get

dressed properly. It got to a situation where he was going out in the street, and saying to strangers, 'Would you mind doing up my shoelaces?' If you think about the cost associated with that, it is just bizarre. As a consequence, obviously, he felt – and this is his description – that it compromised his dignity and his quality of life. It meant he was less confident in interacting with others in his community, but also felt like he was a burden on his neighbours, which is not a preferable thing in terms of both independent living and other people's outcomes.

### **Baroness Campbell**

Richard, what about impact on health services? Are people presenting in the health service more because of changing eligibility?

### **Richard Humphries**

It is very difficult to put some figures around that. There is certainly evidence – more in relation to older people – that unless there is good social care, they will end up in the wrong place in the system. They might end up in hospital when they should not be in hospital, and then it takes longer to get out. We have less evidence of that around working age people with disabilities. However, what we start to see is an increasing number of people developing long term health conditions during their working age years, so I think that may well change.

### **Baroness Campbell**

Yes. Do you think that is something that we are lacking in terms of data on those below the age of 65, and the impact on the health services? We are very focused on older people.

### **Richard Humphries**

As I see it, there are more and more people who are falling outside of the publicly funded social care system. The data that we have about what happens to them is very poor, whether they are older or working age. It is probably slightly better for older people because many of them are in care homes. We know, through CQC and surveys, that for over half of people in care homes, the money is coming from their own pockets. However, because that does not apply to working age people, it is much harder to get a feel on what is happening. Our informed opinion would be that people either fall back on other services like the NHS, they fall back on informal carers and friends, or they go without.

### **Baroness Campbell**

Very interesting.

### **Andrea Sutcliffe**

Could I just add two points to that? One is really thinking about the impact on health services. I think that we should be ensuring that we are thinking about the impact on mental health services, and not just the traditional acute hospital perspective. I do not think there is good assessment and good data, but you could make a reasonable hypothesis around the impact on an individual's mental health wellbeing and the support that they do or do not get, and their ability then to have a full and meaningful life. The second thing is the impact on families who end up caring in these

circumstances, as Richard has just said. Some of the evidence that we have heard is that you get into battles. People's time is spent in battles, and they are seen as a burden, and therefore they are not necessarily able to enjoy a family life where they can be somebody with whom you enjoy their company and all of those kinds of things, because you are constantly worrying about what you are going to sort out tomorrow.

### **Baroness Campbell**

Colin, have you got all the information you need for your answer?

### **Lord Low**

Thank you, yes.

### **Baroness Wilkins**

You have actually started to answer the next question, because it is the impact of the rising eligibility criteria on disabled people's ability to fulfil their family responsibilities and their social roles. Could you expand on that, and give some examples please?

### **Andrea Sutcliffe**

I have two or three things to say. One is going back to the question that we had about outcomes and being clear that somebody's quality of life and their experience of their life is actually an outcome that we should be taking into consideration. Clearly their family life and contribution to the family is important. Secondly, I think that it goes back to what I have just said, which is the kind of burden that an individual might end up being, and actually, they feel it for themselves. We have done lots of social care TV films with individuals who have said, for example, that having access to services like tele-information technology has actually helped them to be more independent. One of the things that they say to us is: 'It makes me feel less of a burden to the people who I'm living with and who are caring for me, because I don't have to ask them to do the basic mundane thing, and I can actually do other things with them'. So I think that there is that sort of guilt feeling that people end up having, which is obviously very detrimental.

### **Dr Marc Bush**

It also makes it slightly more complicated sometimes in terms of familial relationships. I was talking to a disabled lady who was saying that because she had lost her care and support package, she was reliant on her child to care for her. New research that has come out of the Department of Health shows that there are about 40,000 child carers in the UK, and if you consider that there are 69,000 people who have fallen out of the formal care over the last decade, that is probably an indication of where that care and responsibility goes. It does not just go to parents.

### **Baroness Wilkins**

Are there any figures on whether that is rising or not?

**Dr Marc Bush**

The census data that was released suggests that there is an increase in caring responsibilities outside of formal care. I think that it is possibly important to flag here that eligible need is not all of your need. You may have your whole presenting needs, which might be 100 different needs, but eligibility might only look at about 50 of them. So even if you are within the system that extra care burden has to be picked up somewhere else.

**Baroness Wilkins**

How much of your role as a parent, or as a daughter looking after elderly parents maybe, is taken into account in looking at eligibility criteria? Is it taken into account at all?

**Dr Marc Bush**

It varies a lot across the country. Obviously I do not want to get too much into carers' allowance or carers' assessments, which is part of what the new draft legislation does, but it is a very complicated mix.

**Baroness Eaton**

One of the things around child carers is that there is a danger that they fall through the middle, with the Care and Support Bill and the Children and Families Bill, because neither actually takes it as a major issue. I think that is something that needs looking at.

**Sarah Newton MP**

We have been talking a lot about the current eligibility criteria. What I would like to do now is focus on the new proposed eligibility criteria that are within the bill. I am bearing very much in mind what you are saying, which is that so much of the eligibility criteria is about caring for people, when there are identified risks for caring, whereas what we would probably all like to see is more criteria to enable people to participate in life. With that thought in mind, could you share with us your views of the proposed eligibility criteria? In what way could our inquiry be making recommendations for them to be improved, particularly in light of enabling people to lead independent lives in the community and to be able to access employment, and bearing in mind how those eligibility criteria work alongside reforms to PIP or Access to Work?

**Baroness Campbell**

I think you all ought to have a go at that one. It is very important.

**Dr Marc Bush**

I think it is really challenging, because there are two parts to this reform. The first part is to work with the existing criteria, and make slight amendments and set a national threshold, it seems at a substantial level, which means that those extra 36,000 people would drop out of the system. However, in the longer term it is to radically overhaul what eligibility is about. I think all of us would welcome that radical overhaul and re-thinking. The concern of everyone across most sectors is that if in the interim you push eligibility too high, you are actually only containing a very small

group of people within the formal care system. Then when you re-define the system towards a framework that is hopefully based around outcomes, then you have suddenly lost so many people who will not realise those outcomes in family life and employment. I think that in the interim the important thing is to sense-check and re-look at it. It is not a concrete commitment yet, but the idea is that perhaps that national eligibility should be set at 'substantial', because so many disabled people will be outside of the system, and particularly working age disabled people. They are the people who are on lower rates of Disability Living Allowance, so will be losing that, and they might be getting additional payments for the Independent Living Fund. They will also be dependent on a whole range of changes that are going through welfare. So if you were to stack up all of the changes, they will be disproportionately coming out of the greater social welfare system.

I think in the long term, you are totally right. It is to push past the risk-based system, and like Richard was saying, it is really about thinking about what eligibility is. Is it a gateway into formal services that are outmoded? No. It is about creating new markets that disabled people drive, which push the outcomes that they define, but particularly promotes their independent living. I think there are two challenges, because the Government is going to have to resolve both the interim and the long term.

### **Richard Humphries**

I think the bill offers two opportunities and leaves us with one major challenge and headache. One of the two opportunities, I think, is that we can move beyond this very narrow mechanical language of eligibility criteria and instead spell out exactly what people are entitled to irrespective of resources. There are some very basic things like access to information and advice, access to assessment of one's needs, and separate assessment of carers' needs. There are some authorities that are building in other basic aspects of that, offering very low level support, supplying, for example, items of equipment or tele-care where it would cost more to assess than to provide the service. So I think the bill opens up some opportunities to really move beyond eligibility criteria. The second thing is that I think it offers the opportunity to develop a much fresher approach to assessment. At the moment assessment is based on what people cannot do, and assessment should be based on what people can do, their aspirations and social networks. A lot of current assessment and interventions actually reinforce dependency. They create people's dependency on services, which actually makes them even more dependent. I think there is a real opportunity to develop a new approach to assessment, which is produced based on assets, and on what people can do for themselves, as well as what they need.

The third issue is the challenge. Despite the positive step forward with the Dilnot recommendations, I think we are still left with a system that has still got this structural chasm between demography and rising numbers of people that need care and support, and the actual money that we have got in the system at the moment to meet it. I am certainly not saying it is all about money, but we have still got a fundamental issue. Currently numbers of people using services are falling, and they have been for at least three years. Spending on care and support services across all groups – with the possible exception of learning disability – is falling too. As long as we have got this structural mismatch between funding and need, I am afraid we are still going to be having discussions like this.

**Lord Low**

What you have just been telling us really pulls in the opposite direction to the implementation of the Dilnot recommendations, the new funding regime that has been proposed, so that there is more money available to people, but fewer people able to claim it.

**Baroness Campbell**

Actually, we are going to have a session on the Dilnot recommendation, so just a quick one.

**Richard Humphries**

Dilnot was set up to answer a different question, which is: how should the cost of care be shared? He came up with the recommendation that there should be a limit on the sort of costs that people should expect to be bear for themselves, so that is the contribution of Dilnot. It sets for the first time the principle that the state should limit people's liability towards their care costs, but of itself it does not bring into the system significant amounts of additional money to meet needs that are not being met at the moment. That is the challenge that I was referring to.

**Baroness Campbell**

Andrea, can you give us a quick answer?

**Andrea Sutcliffe**

Yes, I will just add something quickly, because Richard and Marc have covered it quite comprehensively. The only two other points that I would make are about how we ensure that the wellbeing principle that is at the heart of the bill actually reads through into the eligibility criteria aspects of the bill, so that we do not have that wonderful kind of kick-off that we have in the Care and Support Bill with the wellbeing principle being highlighted there, and then we lose sight of that when we get to eligibility. I think that is one point. The second point, which is related in a way, is about the issue around how we ensure and enable that preventive services are provided at a point when people may not actually be reaching any sort of eligibility criteria; however, providing those services is actually appropriate for them and cost-effective for the public and the private purse.

**Tom Clarke MP**

I apologise for having been late, but I was dealing with other business. My name is Tom Clarke and I represent the Scottish constituency called Coatbridge, Chryston and Bellshill. I will tell you all about it later. Can I turn to the question about the bill? I know that you have touched upon it a few times. The intention of the bill as described in Clause 1 is to promote an individual's mental and physical health. Now, I would like to ask, in your view, how do you think the challenges that working age disabled people are facing are impacting on their physical and mental health?

**Richard Humphries**

I think there lots of different aspects to it. We did some research last year that highlighted the extent to which people have both physical and mental health problems at the same time, and how many people develop mental health problems because of issues about services they are not getting to meet other needs. I think that is directly relevant to what you are describing.

**Baroness Campbell**

What was that? Where did that data come from?

**Richard Humphries**

I can send you the details.

**Baroness Campbell**

Thank you.

**Richard Humphries**

It is from one of my colleagues, Chris Naylor, and it has been quoted quite a lot. It would appear that we have underestimated the extent to which working age people have both physical and mental health problems at the same time. We have got the numbers wrong in the past, it would appear. There is a very, very strong relationship between the two, and I think it reinforces the need to look at the whole person, and not just the bit of care needs that they are asking about or presenting. I think it is very relevant to the earlier discussion about the impact on the whole family, on children and on children that become young carers. These things start a whole train of actions, which feed through.

**Baroness Campbell**

We are quite interested in that chain reaction, because I think that is where we want to concentrate in our debates in both Houses. Marc and Andrea, do you have anything to add to that?

**Dr Marc Bush**

I think this also goes back to what Richard was saying before, about the bill being a really big opportunity to change the way that we talk about care and support. At the moment, because of the rising and rationing of eligibility, increasingly we are seeing people's needs and the associated costs spiralling. The great thing about the bill is that the intention is to catch people early; so not just create preventive services, but catch people before they actually have a formal need or a more substantial level of need. That is why we are saying that they are captured within the formal care service. There was a recent support by the British Red Cross, which showed prevention at work. It said that if you do not capture those needs early on, they do escalate. You might be thinking I am only talking about people with acquired impairments, but I am not. There is really interesting

research from Mencap and the National Autistic Society, which talks about how the earlier you get people understanding how best to manage their own condition, the less likely it is that their needs and associated costs will escalate. One of the other benefits around what the Government is trying to do is that all parties have acknowledged that, as Richard was saying, there is a black hole. The PSSRU at LSE estimated that there is about a £1.2 billion black hole in terms of funding for care for working age disabled people, and all parties have a consensus that there is a need to invest in social care. I think that is where the Dilnot investments come, but we know that Dilnot, as Richard said, only answers a small bit of the problem for a different group. I think that it is important to think about making sure that disabled people are contained within the system, that they are getting support in a preventive and early fashion, so that perhaps they do receive care and support throughout their lives, but not at a much higher level because they come back into the system at crisis. That obviously has quite a significant impact if not on their wellbeing, then at least an impact in both criminal justice and mental health.

### **Andrea Sutcliffe**

I will just come back to the question that you were asking, which was about the challenges that working age disabled people are facing, and whether that is impacting in itself on physical and mental health. I think what Richard and Mark have demonstrated is that we can see that physical and mental health is connected in terms of people's disabilities, but I do not think we can really answer the question about the evidence base for a consequential impact of those challenges. However, I think that we have an opportunity, if we do move assessment to looking at outcomes, and we do think about not just the initial assessment that people have, but the review and the ongoing work that we do with individuals. We can think about meaningfully using that information to follow people through and to see what that journey is. There are an awful lot of questions that we would all like to have answered, but I do not think the evidence base is there because the research has not been done. However, with a different approach we might actually give ourselves the ability to ask those questions, because we will be looking at the information in a different way.

### **Lord Tope**

From your experience, what aspects of the current fair access to care services criteria would you change, and why?

### **Dr Marc Bush**

I think I would just come back to what to what I said before. The idea that there will be a threshold is really welcome. The fact that the Government's aspiration is to move away from a risk-based system is really welcome; it is what happens in the interim that is still a big concern. Just to echo what Andrea said, I think if the future of eligibility is based on wellbeing and outcomes, that is the right approach. It is really important that disabled people are able to define what those outcomes are, and be the own judge of their wellbeing.

### **Baroness Campbell**

That is going to be quite hard to quantify, isn't it Richard?

**Richard Humphries**

It going to be very difficult to quantify, because whatever criteria or guidelines you have, you have got 70,000 social workers out there individually interpreting them with a whole range of people in different circumstances. We need to bear in mind that we have had the current criteria for nearly 10 years. They were aimed at promoting consistency, and they have not done that. They were tightened up three years ago to try to reflect some of the discussion that we have been having. I would argue that the current criteria in their current form are largely irrelevant, actually. They have very little impact on the actual care that people get, whether they get it, and how much is spent.

**Baroness Campbell**

What would you be looking for?

**Richard Humphries**

As I have described earlier, I think we need to look at defining an essential entitlement that everybody gets wherever they live, and that is very much about assessment, information and advice. We need a different approach to assessment that is much more consistent than the 152 different approaches that we have got at the moment. There are going to have to be some kind of criteria, because we do not have a blank cheque, but I think we need a much clearer framework that differentiates those things that everybody should get wherever they live, irrespective of their postcode, and those things that need to be assessed in a planned and transparent way.

**Sarah Newton MP**

It is a follow up question really, about people who in the past would have had what was deemed to be low level support through social care, and to what extent the new channels of funding could be used to help people. You have got people living with disabilities, who are on disability benefits and can work, and want to work. Those people potentially could be supported through the Work Programme, and the Work Programme in two years can pay for the sorts of things that used to be paid for by social services, such as transport to work. Basically it is carte blanche, so whatever it takes to support that individual into work: that is the promise of the Work Programme. It is my understanding, but correct me if I have got this wrong, because you certainly are far more experienced about this than I am. Within universal credit, as it is proposed, people with disabilities who are working can earn up to £7,000 without any benefit withdrawal. What do you think about these new ways of doing things? It would hopefully come to the same outcome, so that people with disabilities of working age who want to work and can work, but need practical help to enable them to do that, would be funded initially through the Work Programme to get them into sustainable employment. They would generate the income, so they would then pay for themselves rather than going to the social services department.

**Dr Marc Bush**

It is a really interesting proposal. I think you have hit the nail on the head on something that has been missing from the wider debate. We have heard a lot about integration between health, social care, and additionally now housing. There is a lot of money that goes into employment support for disabled people, and the Government is currently thinking about a new disability employment strategy. There is a recognition that that needs to look better at how people have the support they

need to socialise, but also in terms of personal care, as an addition to direct support within the workplace. The only thing I would say about the Work Programme specifically – and I know the Work and Pensions Select Committee have been looking into this – is that the outcomes for disabled people are very low. They are under 1%. So in terms of the Work Programme delivering on that aspiration, I think perhaps there might be a gap. I guess the Government looking again at a disability employment strategy might indicate that there needs to be a new generation of thinking, which again is an opportunity for supporting disabled people back into work. I think the only concern I would have is that if we said that a responsibility then fell to Work Programme providers, you potentially hide the fact that lots of people do need fundamental care and support, which is not aimed at getting them back into work.

### **Sarah Newton MP**

I was just talking about that particular group.

### **Dr Marc Bush**

For that group there is a real minority of people working within the Work Programme who have the expertise to be able to separate the barriers to employment that disabled people face with condition management and then on top of that, health management. I think those things become increasingly difficult. It is not undoable, but there needs to be a lot more thinking on how you would integrate that. It is probably for the next generation, not this Parliament.

### **Sarah Newton MP**

Access to Work and all of these schemes, as you say, need to be really looked at in detail, if we can find some examples of where it has worked well, to make sure that that can be made accessible to everybody.

### **Dr Marc Bush**

It should be re-thought alongside what is an ambitious re-thinking of the care and support system.

### **David Ward MP**

This is an area of personal interest, really. I know we were talking about work age rather than the elderly, which is more prevalent, but the issue of loneliness is one we have seen. Is this an issue for working age people? Does it need to be picked up as an identified need?

### **Andrea Sutcliffe**

I think that it is an issue that we have to be mindful of in terms of the impact on people of working age, who end up being lonely because of whatever reason, in terms of their isolation. Going back to the conversation that we were having earlier, on the impact on their mental health and wellbeing, and the consequences that that can have, I think that it is something that we need to not ignore, and there has been a lot more research and observation around this for older people recently. However, in the past we did not really talk about it, so I think you are right. Shining a spotlight would be important, and thinking about creative ways, as we were just discussing, about the broader range of initiatives that are available, and particularly the work that people are doing around developing

community capacity, while engaging communities in a broader way to provide support, to engage, and to reduce that isolation and loneliness. This is an important way for us to be going forward.

**Baroness Wilkins**

It is really just a question to help me with the broad picture. Given that the aspiration of the bill is for prevention and getting in early to prevent people from getting worse, how far would you say the bill, as it is presently structured, works to enable this?

**Andrea Sutcliffe**

It is a starting point.

**Baroness Wilkins**

A low or high starting point?

**Andrea Sutcliffe**

The aspirations are there, and all the bill can do is set the frameworks. I think one of the really important aspects of prevention is giving people information and getting people talking about these issues in advance and in a meaningful way, at a stage where it can actually make a difference. One of the aspects of the bill, which is about local authorities providing information and advice to support individuals in the local community, is really important. That is very helpful, but the proof of the pudding will obviously be in the eating, in terms of how that is delivered and how comprehensive and supportive it can be.

**Richard Humphries**

I think a real problem in recent years is that the resources that local authorities have devoted to prevention have been really been squeezed, because they have concentrated on people with the highest needs.

**Baroness Wilkins**

All Government policy does; it is all about the most vulnerable.

**Richard Humphries**

Absolutely, so in the short term, I do not think that the bill itself and the act, when it becomes an act, will magic away those really tough choices that we face.

**Baroness Wilkins**

Does it address it?

**Richard Humphries**

I think it is back to money, in part.

**Baroness Campbell**

You cannot forget the money.

**Richard Humphries**

No, follow the money. However, it is not just about the money, and I think if people did get those basic things that I described as an entitlement in terms of assessment, information and advice, that itself would have a significant preventive effect. People often end up in the wrong part of the system, in the wrong place, at the wrong time, because they did not get basic information. There are simple things that we can do that would not cost a great deal of money.

**Baroness Campbell**

On that happy note – because we always have to remember the money, and that will lead us very nicely into the next session – I call this to a close. Thank you very much, Andrea, Richard and Marc. You have done a great job, and anything that you feel we might have missed, please submit to us, because we need the facts, and evidence will be useful. Andrea and Richard, if you can think of any research that may add to what we have asked you, then do send it in. Thank you very much.

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<http://www.ubiquis.co.uk> / [infouk@ubiquis.com](mailto:infouk@ubiquis.com)**