

HOUSE OF LORDS  
HOUSE OF COMMONS  
ORAL EVIDENCE  
TAKEN BEFORE  
JOINT COMMITTEE ON HUMAN RIGHTS

**THE IMPLEMENTATION OF THE RIGHT OF DISABLED PEOPLE TO  
INDEPENDENT LIVING**

TUESDAY 28 JUNE 2011

Professor Peter Beresford OBE, John Evans OBE and Doug Paulley

Stephen Lowe, Emily Holzhausen, Andrew Lee and Marc Bush

Evidence heard in Public

Questions 78 - 106

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Members present:

Dr Hywel Francis (Chairman)  
Lord Bowness  
Baroness Campbell of Surbiton  
Lord Dubs  
Lord Lester of Herne Hill  
Lord Morris of Handsworth  
Baroness Stowell of Beeston  
Virendra Sharma

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### Examination of Witnesses

**Professor Peter Beresford OBE**, Centre for Citizen Participation, Brunel University,  
**John Evans OBE**, and **Doug Paulley**.

**Q78 The Chairman:** Good afternoon and welcome to this special evidence session of the Joint Committee on Human Rights, dealing with our inquiry into independent living. This is the third evidence session and we are most grateful to you for your co-operation in coming along to speak to us today about your concerns on this important matter. Could I at the outset declare an interest? I am Vice-President of Carers UK. Could I begin by asking a general question on the scope of the right to independent living? We have received a great deal of evidence from individuals and organisations about the importance of independent living as a basis for Government policy. Could you tell us, each of you, what independent living means to you? Mr Paulley, would you like to start?

**Doug Paulley:** I have been asked to speak as I live in residential care and my understanding of independent living is from that context, I suppose, about rights and choices in residential care, both actually living there and the right to leave or the rights when choosing whether or not to live in residential care in the first place. I think there are some substantial barriers to independent living within the residential care context, not least of which are the assumptions

that are made about what it is reasonable for people in residential care to be able to expect on a day-to-day basis. Having choice and control over such things as who supports you and when and how; the ability to get out and about; the ability to access employment and education—these are all very limited, as is some involvement in both the policy setting and your everyday experience, your everyday care provision. It is even more difficult trying to get out of residential care in my experience having looked at this quite a lot one way and another. There are barriers in accessible housing or lack of it and if you are in residential care then you do not get priority on social housing lists, because you are classed as adequately housed; some other people who may be being carried up and down stairs understandably get priority. But also, the flexibility of support is not always there in the community to enable people in residential care to access suitable facilities there, to get out of residential care and be independent. Finally there is a big funding barrier. I did not choose to go into residential care; many of the people I live with also did not. So, yes, there should be the right to choice and control as well as getting out of residential care. So that is where I am coming from on the issue.

**John Evans:** What does independent living mean to me? I think that is a very deep, life-changing question and it means a lot of things. I suppose I could say it has changed my life and I know it has changed the lives of many other disabled people whom I have come into contact with. What it means is, basically, it is my life, my work, what I do every day of my life, and the fact that I am able to do that through the support of others like the personal assistant sitting next to me is immense. It is very hard I think to get that message across to people who perhaps are not dependent on others to support them in their day-to-day living. But it has provided me with a life, my work—I have worked widely—and the opportunities and the choices to do the things I want, like you do. I think with the restrictions somebody like myself has, with the kind of severe impairment I have, it is freedom. It is the freedom for

me to be able to do what I want to do, when I want to do it, in a way, because I have people around me who can support me to do that. I could probably talk about this for a long time but it is a very, very crucial thing. A disabled colleague of mine once said, “There are three big ideas disabled people came up with: the social model of disability, independent living and fighting for our human rights”.

**Peter Beresford:** I would come at personal experience from a slightly different place in so far as my personal experience has been in using, over a long period of time, mental health services. I think there are two elements that I would associate with independent living, which—as John has said—have challenged old-fashioned ideas of it meaning something like standing on your own two feet: one, that people have the personal support that they need whatever form that takes to live their life on equal terms with any other, non-disabled person; and two, that they have equal access to the mainstream world that other people inhabit and take for granted. Those two elements are equally important.

I want to base some of my comments today on recent evidence and I want to draw on a project called the Standards We Expect, which was a national project supported by the Joseph Rowntree Foundation, where we spoke with service users, carers, face-to-face practitioners and middle managers, particularly trying to find out more about their experience and understanding of person-centred support but getting a very good picture from a very wide range of service users of how things actually are in the system at present. While we found some really inspiring positive examples, I think we also, sadly, found that on a routine basis a very wide range of different disabled people experience restrictions on the opportunities to live independently, which one can trace to a range of characteristics and factors to do with the way in which services work. I can elaborate on that later if that is helpful.

The other point I would want to make is that we are talking about a very diverse range of disabled people as long-time health and social care service users—people who may have physical or sensory impairments, learning difficulties, mental health problems, life-limiting conditions and so on and so forth. I think that this has developed differently for mental health service users. I do not think many mental health service users are as aware as some other groups of disabled people of the idea of independent living, although they might well aspire strongly towards it.

More recently another model has developed in the psychiatric field. It is called the recovery model and it has a positive to it in so far as it does not write people off who have had long-term mental health problems as people who will never be able to do anything. In that sense it very much mirrors the aspiration of independent living, which is that people can have an equal chance to a life, to controlled choice, to what we have heard. The difficulty that I worry about with the separation of these ideas for mental health service users and the loss of the idea of independent living sometimes is that it suggests that recovery is something that sort of happens and then you are okay, whereas I would say from my experience that, while you may learn to deal with the difficulties you have and you may find a range of informal supports, you have good and bad times: things can go wrong again. Just as someone who uses a wheelchair may have a long-term need for a wheelchair, so mental health service users can have a long-term need for support, more and less at different times and changing in nature, even though they are able again to be an equal and active part of the community.

**Q79 The Chairman:** Thank you very much. In my enthusiasm to tell you that I am Vice-President of Carers UK I omitted to invite you to introduce yourselves, so it is important at this stage for me to ask you all to introduce yourselves and to explain who you represent or what you represent. Mr Paulley?

**Doug Paulley:** I am Doug Paulley, in lieu of an organisation that effectively represents people in residential care. I understand that is my role.

**John Evans:** I am John Evans. I work as a disability rights consultant and I am living in Hampshire currently. I am part of the Hampshire Centre for Independent Living, but I have spent quite a lot of my life also working at a European level trying to promote and develop independent living in other countries, particularly in central and eastern Europe.

**Peter Beresford:** I am Peter Beresford and I work as a professor of social policy at Brunel University, but equally important for me from my personal experience is that I am chair of a national, independent, what people call ULO—user-led organisation or user-controlled organisation and network—called Shaping Our Lives. We are made up of and work across a very wide range of disabled people to increase the say and the control that people have over their lives and the services that they use.

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

**Q80 Baroness Stowell of Beeston:** I am Tina Stowell. Can I ask my first question to Mr Evans, please? I wondered whether, as someone who has campaigned for so long on independent living issues, you could tell us what the UN Convention, in particular, has done, if anything, in terms of adding to the protection of the rights to independent living.

**John Evans:** I think the whole spirit and the whole focus of the UN Convention is very much around independent living. The convention is not just Article 19. It is all the other articles, too, which encompass different aspects of independent living: personal mobility, education, employment. Almost every article is about independent living. I think one of the biggest things about the convention and the fact that it happened is the recognition of independent living, the high priority that it has given to having an article on that. Excuse me for this; it is unusual for me to not be able to speak.

**The Chairman:** Take plenty of time.

**John Evans:** I think it has brought enormous scope, not just for us in this country but for people in other countries, and I think that it provides this country with a platform in some respects to show the world something. I think we have quite a good development of independent living in this country and I think the independent living movement in the UK is looked upon very highly in Europe, where I do a lot of work. People there look to the UK in terms of independent living. I think we are in a very good position in this country to again take the lead at a time—perhaps not the best time—where we are having cutbacks to services. I think it could not, in some respects, have come at a better time. We are living through difficult times, difficult periods, but we have got now an international legal instrument to enable us to really move ahead with independent living and make that a right. I think that is the essential thing about this convention. It is making independent living a right and, before, we did not have a right to independent living. We did try, in this country, for a long time, to get a Bill for independent living through to the statute book, through a number of Private Members' Bills, but we never quite made it. So, to a certain extent at least we have this international legal instrument now to put within the national framework of our UK legislation to make that happen. We had to move beyond entitlements because, before, we had entitlements to services and not everybody was guaranteed to get those services. So I think it has brought a tremendous amount of scope and, as I said, I would like to see this country still lead and take it forward because we have the people, we have the social care structure and we have good policies. For us and for the world, for every disabled person, it is good news.

**Q81 Mr Sharma:** Mr Paulley, we know you have practical experience of campaigning on the rights of residents in residential settings. Could you explain a bit more about the

challenges faced by disabled people living in residential settings who want to rely on the UN Convention to challenge limits on their rights to independent living? Are there any specific changes that Government or local government needs to make to enable people like you to access the right to independent living? I must declare my interest as well, in that my former job was working in learning disabilities.

**Doug Paulley:** There are many barriers to independent living within residential care. A lot of people have this state of learned helplessness, where whenever they have tried to ask for something often it has not happened or there is a genuine fear of retribution when they have raised things because there is such a power imbalance in the system. I think there are possibilities for change, and change that does not necessarily cost more. One of the problems I feel is that there is not effective representation of people living in residential care one way or another. There is no user-led organisation that has many people of that experience, which is why I am asked to speak at such events. I wonder about the possibility of introducing a residential care commissioner, like the Victims' Commissioner, to speak to the views of those who are unable to, one way or another.

Another possibility is localising regulation more. At the moment the perception is that the Care Quality Commission is not able effectively to regulate social care homes to ensure people's independence and choice. People I have spoken to in the residential care field, including service users, have had the impression that it was more likely that they could get independence and choice on the agenda in their home where there was a small, local inspection team instead of a large inspection team amalgamated with health, which often has different goals and aspirations for people. This is all around control over the environment where people live and ownership of their home, if you like—not in terms of money but in terms of ownership of their home as where they live. I think that there should be a return to outcomes-based systems like the national minimum standards and preventive versus

reactive. At the same time, though, there has been such constant change within the regulation system and the provision system in residential care that at the same time as advocating change I would also advocate some consistency. I would also argue that there needs to be further promotion of social care—perhaps a reduction on the right to buy, so that you can have more accessible housing available for people. Maybe it would also be possible to extend direct payments or individual budgets to people in residential care—not that I think that that has worked as a universal panacea elsewhere, but it would treat people in a similar fashion to people in the community. There is perhaps this inbuilt assumption that people in residential care would not be able to get the benefits out of direct payments. Those are some suggestions.

**Peter Beresford:** I wonder if I could just add to what Doug has said from the research that we have recently reported, which very much chimes in with what Doug said. For example, we heard about people who are wheelchair users in homes who were not allowed to use a cooker, with the argument that their hands touch the wheels of their wheelchair and therefore might be contaminated, that they could not use the fridge to take out food because similarly they might be dirty, or that they are not allowed to use the kinds of things that we would take for granted in our own homes, such as for making a cup of tea, which was left to staff, and so on. Also, people talked about always having to have risk assessments made so that you could do very little without it being risk-assessed: someone saying you are going to the supermarket to do your shopping—something that everyone does—and you have to do a risk assessment on it.

In terms of a more complex lack of support, we heard, particularly from families from black and minority ethnic communities with children with learning difficulties, that they felt very unfamiliar with and frightened of the services. Where there was an initiative to link up with those families, it worked extremely well. Similarly, we came across cases where there were

adults with learning difficulties whose families had not been given the support, advice and information to help those adult children become independent and would then be part of a process of restraining the chance of those adults having independent living. There were things like people with communication impairments not having basic technology assistance, which they should have had.

I would reiterate what Doug said, which was that there are—and perhaps there are increasingly—problems of money and resources, but I think we would also argue from the research that we have carried out, working with a wide range of services and people, that there is a problem with what we would call culture and it is a culture that often, as people said, assumes that it knows best for them or assumes that it knows what they should have and what they are capable of. It is a culture that is sometimes built into organisations, into ways that people learn to practice and into broader attitudes. The picture prevailing from our study, which was a large study, was not of the extreme abuse that we have recently heard about, for example near Bristol, or the terrible financial insecurities that we have heard about with Southern Cross, but of a much more matter-of-fact but none the less very important restriction operating on a wide range of disabled people really making the kind of independent living we are talking about very, very difficult. Yet where people experiment and try, we can see that it can really be done and it can be done in residential settings just like anywhere else.

**Q82 Lord Lester of Herne Hill:** Can I ask Mr Evans about the legal framework? You gave written evidence that we have one of the best legislative frameworks in Europe and I assume that that refers to the Equality Act, the Human Rights Act, the Welfare Reform Acts and care legislation. Is that right? Is that what you were referring to when you referred to legislation?

**John Evans:** Yes, but also the direct payments Act, of course, which was pretty key to independent living. We are one of the few countries in Europe that has such legislation, as well as the DDA—the Disability Discrimination Act—and some very good policies like the independent living strategy and so on. Both the Department of Health and the Department for Work and Pensions have done some groundbreaking work establishing that framework, I must admit, alongside disabled people who were involved in helping to develop that work. We certainly have a good framework. It has its gaps and I think perhaps some of the gaps in terms of trying to bring about the requirements of Article 19 would be in particular around issues of more joined-up thinking and more joined-up working, particularly within Government Departments. I think all Government Departments need to be signed up to this convention, not just the DWP and the Department of Health and perhaps the Cabinet Office, which are the ones that are mainly taking the lead.

I think there is that need for joined-up thinking and there is probably a need for more direction for local authorities as well. I think the problem we have in this country is around how local authorities interpret the current legislation and how it gets implemented in those local areas. People like ourselves, who see and meet disabled people from all over the country, realise that some people in some parts of the country will get a much better deal than others. I would like to see the gap being filled by Article 19 being introduced, where there is a level playing field on which disabled people from all parts of the country have access to it.

There are weaknesses in the way our system works, to a certain extent, but I think we have a framework. Perhaps now the DWP needs to try to strengthen the independent living strategy so that it fits within the realms of Article 19. The two should be worked together so that things can really begin to happen. It needs to be implemented. It needs a Government role; it needs a local authority role. I move around the country and I am still

amazed—absolutely astonished—by the amount of people working in local authorities who are not aware of the UN Convention, which is quite extraordinary. People who you would think, given their profession, should be aware of it are not aware of it. Somehow it is put aside and some people do not even know that this country has ratified it and signed the Optional Protocol. It is quite alarming. There is a lot of work to be done in those local areas—both nationally and locally.

But we have got a framework. We are in a position, as I said, more than any other European country—and I know this categorically—where we can really push ahead. However, people in Europe are now looking at the UK and reading with absolute astonishment the publicity that is going around about the enormous cutbacks in services and the potential that the Independent Living Fund might even be stopped in 2015. They ask, “If this can happen in the United Kingdom, my goodness, what is going to happen in our country?” There is that kind of thinking going on beyond our shores. That is why I would like this country to take the lead and show the rest of Europe, “Look, we are still the experts in this field and it is not going to be destroyed”. We are living in a difficult time and all our countries are going through this crisis and we have to address it.

Unfortunately, my feeling is that this country went ahead, particularly around the Independent Living Fund, and made some decisions a little bit prematurely without thinking about the long-term impact on the lives of disabled people. There certainly could not have been a very deep look into the future to realise what would happen. I cannot envisage 2015 if suddenly the Independent Living Fund is taken away. It would probably mean me having to go back into residential care, which I thought I had got out of in the late 1970s.

**Q83 Lord Lester of Herne Hill:** I have not really put my question properly. You have travelled well beyond what I was going to ask you and it is very helpful that you have, but all

I really wanted to ask you—I have to admit that I am a lawyer, so I would, wouldn't I?—is about the legal framework, not about policy or practice. Parliament has recently passed the Equality Act 2010, replacing the disability discrimination legislation with brand-new legislation, and we have the positive public sector duties in the Act that we implemented, so I am just focusing on the framework itself. Are there any gaps in the legal framework—not in application or policy—that have still not been filled by Parliament in the 2010 Act or otherwise? Or are there any worries about the statutory duties that are being implemented under the Act? You have dealt with a lot of other stuff; it is just that part I would be grateful for your help on.

**John Evans:** Yes. The legal framework is there; I think we have a fairly good structure in this country to make things happen. But it has to be implemented. This is the difficulty.

**Q84 Baroness Campbell of Surbiton:** My question is for John and a bit to Doug as well. Sorry, I will have to call you by your first names; it would be just too strange to call you by your surnames given the work we have done in the past together. In your written evidence, John, you talk a lot about freedom of movement and how there needs to be freedom of movement for independent living to be truly successful. Could you explain to us what you mean by this and what implications there are for the Government's ability to fulfil Article 19 obligations?

**John Evans:** At the moment, to give you a personal example, if I was offered a job tomorrow in Edinburgh, I simply would not be able to take that job, because I would not be able to move my personal assistance package from Hampshire to Edinburgh. So that is a

violation of my right to seek the kind of employment I want to. It is restricting me from moving within my own country.

**Q85 Baroness Campbell of Surbiton:** What has stopped you moving?

**John Evans:** The fact that my local authority would not continue to pay me and then I would have to renegotiate another deal with another local authority. That is not always guaranteed, because different local authorities have different criteria for addressing these kinds of issues. The eligibility criteria in some cases are not the same as in others. As well as the access issues, I would have to find accessible accommodation and housing and all the rest of it. It is not easy; there are a lot of structural barriers I would have to personally overcome to be able to achieve that. That is what I regret about there not being portability of care packages, as such. I know you have been doing some sterling work in the House of Lords trying to ensure that this can be addressed, but at the moment it is not happening in practice.

**Q86 Baroness Campbell of Surbiton:** So are you saying you do not have a legislative right to move from one place to another?

**John Evans:** That is right.

**Baroness Campbell of Surbiton:** I do not want to put words into your mouth.

**John Evans:** Well it is a violation of my rights that I cannot move from one place to another if I have a new job, because I could not exist without my care support package.

**Q87 Baroness Campbell of Surbiton:** Would that be the case for you, Doug, in residential care?

**Doug Paulley:** Yes, there are the standard barriers of finding appropriate provision but also the added barriers of being uncertain whether the receiving local authority would be prepared to fund.

**Q88 Lord Morris of Handsworth:** My question is primarily to you, Doug, and there is a supplementary as well. Quickly tell us please how you think the Government's policy on residential care charging fits with its wider intention to ensure that work always pays.

**Doug Paulley:** There is somewhat of an anomaly here. By default in this document Crag—*Charging for Residential Accommodation Guidance*—after £20 the money that you earn is taken pound for pound from your contribution to the home. In other words, every pound that you earn over that goes towards the home. This is different from the situation in the community, where councils have some leeway as to setting charging regimes, but I understand it is not pound for pound. While there is theoretically a right for local authorities to choose to waive that to some extent if they feel it is of benefit to people's independence, they are generally unaware of their right to do so and it is discretionary. Residents are also almost entirely unaware. To give an example, Leonard Cheshire Disability, which I understand has 2,100 people in residential care around the country and specialises in people under 65, were not even aware until it was raised that there was this provision that people could earn, but they were also not aware that people by default were unable to earn. So it seems somewhat of an anomaly, to say the least. The Government chose not to address the issue; they did an impact assessment and said that because it does not affect a significant number of people, it is not worth parliamentary time. That was back last year. However, I think that this perhaps says more about assumptions that are made about people in residential care than it does about this barrier, the assumption being that people in residential care will not have the ability, maybe, or willingness to earn and to work in some meaningful way. But I think having

that rule there at all is quite discriminatory and contrary to the Government's stated commitment to helping people to work.

**Q89 Lord Morris of Handsworth:** Thank you for that, Doug. I indicated that I had a supplementary and, if one of your colleagues wants to come in, they should please do so. Have you any ideas about how changes to the charging rules could be made in the current economic climate?

**Doug Paulley:** The silly thing in my view about the whole situation is that if you had a sliding scale or had equivalence to the funding system for domiciliary care in each council, then nobody seems to lose out. You, as a person earning, pay more towards the home; you also pay taxes. The country hopefully benefits from your experience and involvement in whatever way. It does not cost anybody any more. In fact, by having this default rule of pound for pound, they seem to be stopping people earning and providing employment and so on. I think it would just be a simple case of correcting this small anomaly. While that would not in any way significantly reduce the problems that people in residential care have in getting jobs, it would be an easy step in the right direction, I think.

**Peter Beresford:** It does seem to me there is a broader issue here, both for people living in residential services and for people in other settings of working age or who would want to be in paid employment. One of the projects that we were involved in with our research project—it was a research and development project, so we tried to do things with people—was about young disabled people living in residential services. There are all sorts of issues for them, some of which we have touched on already. Many of these young people want to be in employment and want to have a life that is like the life of their peers who are non-disabled. There are all sorts of problems, such as to what accommodation they will be able to move and how much mobility they will be able to have, bearing in mind what we have heard from

John and Doug. I think those things are important, but there are also, of course, broader issues about the accessibility of the labour market.

One of the issues that concerns me very much, which takes us to a broader place but is still very closely relevant to what Doug said, because I think it all starts with some very old attitudes, is assumptions that some disabled people are inevitably dependent and assumptions perhaps that some other people identified as disabled will only work if it is presented as an obligation that they have to avail themselves of. I think there is a problem that we have not paid enough attention to in the context of independent living and human rights, which is thinking about employment, as well as other forms of activity and work, as a right rather than thinking of it merely as an obligation. I have to say that most people I meet—and I am thinking particularly about mental health service users here—may have restrictions on how much they can be in paid employment, but most people want to be in employment. They may not be able to be in employment all the time; there may be times when they cannot do it and they may not be able to do it full time and need some degrees of flexibility. But assumptions that there are large numbers of disabled people who will only get off benefits if a stick is applied is a problem, I think, which is why we have got the mindset that Doug has touched on. I hope we can, as part of our thinking on human rights, think more about choice and control and independent living, employment and the nature of the labour market—the way, for example, that it greatly stigmatises mental health service users and I think also some groups of people with learning difficulties. But this is not a competition; it applies very generally to many disabled people. We really need to do some modern thinking on that.

**Q90 Lord Dubs:** We have received evidence that failure to take a holistic approach to current policy changes and budget cuts is resulting in a disproportionately negative impact on

disabled people's access to independent living. Do you have any experience of this? What do you think Government can do to ensure that it takes a more holistic approach to policies as they affect disabled people's lives?

**Peter Beresford:** One of the concerns I particularly feel now—again, I think it applies widely to disabled people, but it has emerged particularly in discussions among mental health service users as a great cause of alarm and distress—is the lack of connection that there seems to be sometimes in our thinking in relation to people who are disabled as people who may need support from the health and social care system and people on the receiving end of the welfare benefits system. A case came to my attention very recently that for me sums up the way in which there is a need for catch-up within our understanding of rights and the realities of policies as they are currently being interpreted in relation to these two different sectors and the way that they are sometimes impacting at odds with each other on any person's life. The case involved a middle-aged woman, who six months before had had a major bereavement and was therefore suffering serious psychological difficulties. She also had significant impairments and was on ESA—Employment and Support Allowance—and then received notification that that was going to be terminated. Because of her bereavement she happened to have the good fortune to have a social worker working with her who was then in a position to advise her that this was something she could appeal against in a way that could make sense to her—a woman whose English is still limited—and take forward the process of appealing. That is what was done and of course an appeal was submitted to the process. I was told that when the social worker and the appellant got to the appeals tribunal, the chair of the tribunal said to them, before they had said anything further, to reassure them, “Your case has been accepted and the previous ruling has been overturned”. For me hearing that, the rapid rush to an understanding that there was an illegal system made me really worried and confirmed the fears that I have when I listen to so many mental health

service users, particularly those who are seriously distressed about the processes that they are currently undergoing, such as medical evaluation through organisations like Atos, which I think are not consistent with and have outrun the legal safeguards and the aspirations we have in the system. John is right to say so much about the way in which this country is held in respect internationally, but the recognition that there may be in the health and social care system for people's situations is not necessarily matched in the benefits system because of the rush to judgment that there seems to have been with quite urgent calls for welfare reform. I am worried about that.

**Doug Paulley:** I have concerns about two specific cuts that are proposed. One is the Independent Living Fund, which John and other people have already given substantial evidence on. The other one is the proposed cutting of mobility allowance for people living in residential care, which a lot of my fellow residents have raised concerns about. There are concerns about this assumption that we are equivalent to people in hospital, which I think is invalid. This idea that there is double funding—that the local authority already provides for our transport—just does not happen on the ground. In any case, if control of the funding for mobility were to move from us to the local authority, I think that that would remove some of our choice and control. We have also been concerned about the way in which this has been introduced with apparently no consultation or involvement of the people directly affected by it. The Government stated the other day that, while they are conducting their review into this decision to cut mobility allowance, they have no intention of publishing the results of it. If this Bill is passed as primary legislation, so that this does not have any recourse to Parliament again, it leaves us all very uncertain and concerned at what for most of us would be a 69% decrease in our disposable income. It would have a massive effect on our ability to get out and about and be a meaningful part of society.

**Q91 Lord Dubs:** The Government have told us that, although difficult choices are being made to tackle the deficit, they intend to ensure that disabled people with the most difficulties are effectively supported to live an independent life. They stress independent living is “not just about money”. Do you agree with the Government’s assessment that meeting the obligations in the convention is not just about money?

**Doug Paulley:** I agree entirely. It is to a large extent about changing cultures and attitudes, which is in some respects more difficult, even. It is about recognising people’s right to self-determination and respecting their ability to have that, which I think can be more difficult.

**John Evans:** I would go as far as to say—and perhaps be a little cheeky—that the idea for the Big Society probably came from disabled people in the beginning, because in some respects you could almost say that that is how independent living started. It started really by people sharing experiences together on very little and that is where peer support came in. It is extraordinary how much was achieved on very little. In the early days when the first independent living schemes were being set up in this country, one director of social services, when he was asked about the benefits of independent living compared to the provision being provided by social services, said, “I can guarantee that every pound spent living independently is a pound far better spent than anything else I know of yet”. That was a director of social services some time ago. I think a lot has been achieved, but money is not everything and people within the independent living movement have shown what can be achieved by working together—the whole development of the user-led organisation was developed on a shoestring, almost, and now it has become embedded in the policies of this Government. Having said that, we need funding too; funding is essential. But a lot can be done without it. I worry these days about people being forced into the so-called Big Society notion of supporting each other; you cannot force people to do things in local communities if they do not want to do it. Independent living happened because people knew it needed to

happen and disabled people supported each other. You have to have some kind of purpose and commitment by local communities to be able to work together to rebuild society in the way I think it is being teased out at the moment.

**Peter Beresford:** I just wanted to make the point about money that one of the issues that is not talked about enough is how we make the change. In 2010, the Joseph Rowntree Foundation, Shaping Our Lives and Ipsos MORI carried out a small study, talking with service users, carers and local authorities just to find out how they were going to approach making the cuts that everyone knew they were going to have to make. One of the worrying things from that very preliminary study was that it was those local authorities that already had the best involvement of their public and local service users and disabled people who were likely to make the cuts in the most helpful way possible, so there is a real difficulty when you make change that you may make change in very negative ways. Just to pick up on what John said, I cannot help but draw attention to the example of People First in Lambeth, a self-advocacy organisation of people with learning difficulties that my organisation works with and has links with, which has worked so effectively locally and beyond in two senses. It has offered training and skills development to other people to help them understand what works best in providing services and support, but of course it has also equipped a whole lot of people with learning difficulties themselves to take on new skills, tasks, confidence, sense of self and self-esteem and the rest. I know from talking with those people that people have been shattered by the fact that they have lost their funding as part of the cuts. It is true that you do need pump-priming if you want a Big Society where people take a bigger part, although I am always amazed just how much so many people do anyway. There has to be pump-priming to make things work. We know that in business just like we know it in the community. I

always worry about assumptions being made that, because we have to do things cheaper and because public spending must be cut for the present, that may be how it needs to be for the future. We need to think about this very carefully and be methodical about it and make sure that those people, as we mentioned, who might be seen as the most vulnerable are equally recognised and included, even if they do not have a powerful voice either in the House of Lords or the House of Commons.

**Q92 Baroness Campbell of Surbiton:** So it is not all about the money, but money is tight. I would like you to drill down, if you can, in light of the proposals in the Comprehensive Spending Review. Do you think that there are any specific changes to Government policy that could better meet the UK's obligations in the UN Convention without increased funding? That is to all of you. No specific changes?

**The Chairman:** Perhaps you could reflect on that and write to us, because I think it is an important question but may not be one that can be easily answered at such short notice.

**Peter Beresford:** There are things I would want to say. I noticed today hearing about universities—in one of which I am very pleased to work—that the Government are thinking about introducing competition and then there is immediate mention of the private sector. To pick up on what I think both Doug and John have said, we have several sectors here and the most exciting, emerging and radical sector for me is the user-led sector. Yet, despite the evidence we have from research of the value that that sector can contribute in all sorts of senses as an employer, as a service provider and commissioner, user-led organisations are still not really getting any kind of equality in terms of opportunities to be part of the market, to develop the unique capacities they have to match the rights and needs of disabled people and, of course, to take on the task, which they have always been very skilled at, of recruiting disabled people to employment and to new roles and tasks in our society. I would hope—

and this picks up on what you said about providers—that there could be a real emphasis in reality on a market that is equally open to user-led providers and local providers and where an emphasis is placed on people having opportunities and increased life chances through the employment that they can offer as well as perhaps the better services that they can offer. If there is one thing we have learnt lately—I think we have learnt the lesson; even the money people tell us the same—it is that we cannot really just go to the most unconstrained approaches to funding private sector organisations if we are really concerned with securing the rights and needs of service users too. I am not making the point that I know some people make, which I think is a very unhelpful and arbitrary point, that profit and meeting need are just incompatible. That takes us nowhere. What I think does take us somewhere is recognising the very real contribution that a diverse market would have. That must mean a much bigger role, supported by Government at central and local level, for user-led organisations and services.

**Doug Paulley:** I agree entirely with that. The Government should be recognising that organisations for disabled people are often not democratically representative of disabled people, particularly in the residential care market. They are run by non-disabled people; often they run residential care homes. I am concerned particularly that funding is going to charities that have campaigning wings in those circumstances. For example, Leonard Cheshire, Scope, the RNIB and other such charities that run residential care funding are not effective representatives of the people who live in their homes and should not be taken to be so. As such, user-led organisations should be given that role. That might make a big difference, I think.

**The Chairman:** I thank you all for your evidence today. There are a number of questions that we would have liked to have covered, but we will write to you with those questions. If

you feel that there are issues beyond those particular questions that you have not had an opportunity to raise with us, then please write to us as well. Thank you very much.

### **Examination of Witnesses**

**Stephen Lowe**, Social Care Policy Adviser, Age UK, **Emily Holzhausen**, Director of Policy and Public Affairs, Carers UK, **Andrew Lee**, Director, People First, and **Marc Bush**, Head of Policy, Scope.

**Q93 The Chairman:** Good afternoon and welcome to the Joint Committee on Human Rights. For the record, could you all introduce yourselves, please?

**Emily Holzhausen:** I am Emily Holzhausen. I am Director of Policy from Carers UK.

**Stephen Lowe:** Stephen Lowe, Social Care Policy Adviser, Age UK.

**Marc Bush:** Marc Bush, Acting Director, Policy and Campaigns at Scope.

**Andrew Lee:** Andrew Lee, Director of People First. To my side is my support worker, Chloe.

**Q94 The Chairman:** Thank you very much and thank you for coming along today. Could I begin with a very simple question? Could you explain to us what independent living means for the people whom you represent?

**Andrew Lee:** Independent living is taken for granted by people without disability. It means getting our human rights and it is equality too. It moves away from dependency and vulnerability. As we grow up, our brothers and sisters have independence. We have to fight for everything: having children, having a job, living independently. These are things that people without disabilities do not have to fight for; it comes as second nature. We have to

fight tooth and nail for having the audacity to say, “This is actually what we want”. Everybody we come across says, “You will not be able to do that; you are incapable of doing that; you are not able to do that”. We have to fight tooth and nail for basic things that people without disabilities take for granted day in, day out.

**Emily Holzhausen:** I think that is a very good, very clear interpretation of independent living for disabled people. I would add to that, coming from Carers UK and representing the families who have disabled people within their families and also care for them, that this is really key to disabled people’s independent living. If you do not give disabled people the right kinds of services and you take the care that families provide for granted, disabled people cannot live their lives independently, nor can the rest of the family members. It is really important and I think that aspect is often not looked at. Disabled people are often seen as being in isolation—I will touch on that—but disabled people live in the community; they have a variety of networks of support and they live within families and have family members just like everyone else. I think that is where some of the changes that we are seeing are not really understanding how people live in the community today.

**Stephen Lowe:** As Age UK represents older people, a key point to make is that all the research that I have ever seen into what older people want from social care shows that what they want is exactly the same as what younger disabled adults want, which is to be able to have control of their own day-to-day lives, to have a life and to be able to make a contribution to society. That is a point that I think often gets overlooked in the way that social services support older people, which often assumes that once people get past 65 they have a reduced need to be engaged with society and to make a contribution to society. Independent living does not just mean not being in a care home, although I think it is very important that we look at what independent living and personalisation mean to people who are living in care homes. It is not just about personal budgets; we also need to look at what

personalisation means for someone who does not want a personal budget and receives local authority services.

**Marc Bush:** I do not want to repeat what everyone has said. There are probably three key areas. One is making sure that disabled people and their families have access to the rights, entitlements and resources they need to live a fulfilled life according to the things that they want to do. The second thing is that they can take and make opportunities, as Andrew was saying, that everyone else takes for granted. I think the third area is about understanding the social participation and contribution that disabled people make to our communities and recognising that value.

**Q95 The Chairman:** If we can move from what you and your organisations understand by independent living to your perception of the Government and local authorities, do you feel that the Government and local authorities understand this right to independent living in the context of the UN Convention?

**Marc Bush:** I would probably say no. It is very varied. Government and local authorities have a very mixed approach on their understanding of independent living depending on what context they come from. People from a health background particularly find it more difficult to understand the social barriers that people face. Definitely I think there is a lack of awareness of what the convention means, what independent living means within the context of the convention and, as we have been talking about, how it can be used as an empowering tool to enable disabled people to become equal within our society.

**Emily Holzhausen:** I would say that there are two problems, despite pieces of legislation such as your Carers (Equal Opportunities) Act, Chairman, which gave carers a right to have a life outside of caring and gave them additional rights. I would say one is still a persistent attitudinal problem towards families, which is an assumption that they will take on care. That

is why those rights are so important—checking that people do wish to care and that is the wish of all the family members included. Secondly, where you come across very hard-pressed professionals who do have the right attitude to independent living, the lack of social care funding and of funding locally is really inhibiting their ability to deliver what they see as independent living for disabled people and for their families. When we did a large-scale consultation among our membership about what their key priority was, alongside a decent income—to be free from poverty—was better services for disabled people. That is the goal of families. I would say it is still a question of shortfall of funding and attitudes.

**Stephen Lowe:** Over the last 20 years or so, I think the concept of independent living has increasingly moved over to a sort of consumer model of service use, which is particularly evident with direct payments and personal budgets, where the idea is that the person who gets the services is empowered by having their own budget. Now that is important, but I think for older people it is difficult to be an empowered consumer. A lot of that has to do with the circumstances in which older people tend to start using services; it is often on discharge from hospital, when people have to make decisions in a hurry. People are often dealing with new life circumstances, they have very little information about what services are available and they are often too ill to be able to get or to digest the information. If they get a service and they do not like it, it is very difficult to exit from that service. For example, if you have problems with a care home, people are often too ill to leave one home and go to another. So there has to be something other than empowering people through the consumer model. Voice is important; it is important for people to continue to have rights to care and the ability to implement and take advantage of those rights. In answer to your question—does the Government understand independent living?—I think how the Government responds to the Law Commission review of community care law will shed a lot of light on that question. The other aspect of independent living that sometimes gets

overlooked is that it is not just about using services; it is often about being in a position to act with other people collectively and to create support networks as well as being a service user. I think that is also important to independent living.

**Andrew Lee:** I would say that local authorities and the Government have very limited understanding of the issue and often the support that is needed to help you make the choices is not there. If the support is not there, the person does not have a voice; they cannot make an independent choice. If they do not have independent support, they cannot make an independent choice and they are railroaded into making one, two or three choices at the convenience of the local authority. I think that is wrong. People have great difficulty in making complaints. Our complaints policies when things go wrong are not fit to meet our access needs and they need drastic relooking at. If you can make some recommendations there, I would greatly appreciate it if you could look into the complaints procedures and how people can actively make that fairer and easier to use, not just for people with learning difficulties but also for family members as well. Because people with learning difficulties—some of us do have families.

**Q96 The Chairman:** Let me follow on now by placing ourselves very sharply in the context of the spending review. Many witnesses have told us about the importance of social and economic rights in implementing independent living but also about being aware of the severe financial constraints before us. At the risk of paraphrasing a former politician no longer with us, it is really about politics being the language of priorities. What is your response in the present set of circumstances, where we are faced with these constraints? How would you address this question of priorities in terms of independent living? How would you argue that case?

**Andrew Lee:** Funding social care should be more of a priority. If I can put it this way, if the cuts proposed for social care were on the NHS then our nation would be in uproar and politicians' lives would be a nightmare. But for some reason funding social care is not a priority and therefore the need spills over to our hospitals and in some cases to waiting lists or people in beds because the social care is not there. If you want to prevent that from happening, then the same priority for funding our NHS should be provided for our social care, not just in money but in minds and hearts and in principles too. People need to know that, if they made the decision and it went belly up, they are the people who will be accountable. If parents stopped working and stopped providing support today, you would realise that. Listen, think and then act. Listen to us.

**Emily Holzhausen:** I wanted to build on what Andrew said. I think Monday, when Andrew Dilnot and his Commission on the Future Funding of Social Care reports, will be critically important. Within the current constraints, as you said, Chairman, I think there is a short, a medium and a long-term plan that we need and we need some bold decisions, political consensus and action, otherwise independent living for disabled people and their families will not be a reality. Worse than that, I think we will see lots of families in poverty and people living in circumstances that we all deem unacceptable. The other thing that I would like to see more of is the proper, robust use of the equality impact assessments to look at where costs are being built up across the system. To use the example and to follow on from what Andrew said, if you do not provide enough social care—for example, around one-quarter of people have to give up work because they cannot juggle that and look after families, so not only does the disabled or older person have a poorer experience and not necessarily live in the way that they want to in the community, but their family member has to give up work—that is a loss to the economy; it is a loss to business. In Europe, places such as France and Germany have looked at using the care sector as a growth market. How many wins could

that be? Investing in that would be a win for disabled people, more services and independent living; it is a source of employment for people; and it is a growth capacitor for GDP. So I would like to see some bold forward-looking proposals from Government to look at growing the care sector as a contribution to our economy and productivity. That way we also enable families to live more independently.

**Marc Bush:** The politics of this are extremely difficult but I think there are some really serious policy changes on the horizon that are going to undermine independent living. They come from both national cuts and activity that is happening at a local level. A lot of those are undermining the continuity of services that disabled people and their families need in order to assert independent living. That includes the reform that is happening around the DLA assessment into the Personal Independence Payment; the removal of the Independent Living Fund; the changing of eligibility in a local area for social care; and ending or devolving community care grants and crisis loans. All those things are taking away the infrastructure that allows disabled people and their families to live independently and to start growing the resilience they need to do so. That real core of continuity of services that is being lost could have a big detrimental impact in the future. I think that, if we are looking for priorities, that is about looking at how we retain in the future some of those things to grow the opportunities that disabled people will have for independent living. The big questions that remain are: what is the future for the Independent Living Fund—both the resources and the support people used to get—and what is the future for social care, as someone said, and how does that link to employment support, for instance?

**Stephen Lowe:** I would agree with all those comments. The problem is that we are making quite long-term decisions about the future of social care funding, which will affect funding for the next generation or two in the context of the worst financial crisis that the country has seen since the war. We should not be railroaded by the short-term position into making

wrong decisions about the longer term. I do not think that it is possible to cut social services without there being infringements of people's human rights. Even if we manage to provide care of a high standard, there are still all the people who do not get care. What we are seeing at the moment is local authorities restricting eligibility criteria in some cases to people with critical needs under FACS criteria. The human rights of people with substantial and high levels of need are likely to be affected by not getting services. I think that whether the money comes from the state, whether the Dilnot commission comes up with new ways to make insurance products available or whether people have to pay more themselves, there will have to be more money in the system in the future.

**Q97 Mr Sharma:** Each of your organisations represents people who may have difficulty expressing their choices and having control over their lives, such as people with significant cognitive impairment as a result of dementia or learning difficulties, for example. What do you think are the particular implications for delivering the right to independent living protected by Article 19 of the UN Convention for these people? It is a long question; is it clear?

**Andrew Lee:** That is fine. I was just trying to shorten my answer. There needs to be a mandatory right in law, set down by Parliament, for advocacy. There needs to be a self-advocacy organisation that works with decision-makers in every town and city. I got a message today that there are two people with learning difficulties and autism who are having their child taken away from them. They badly need independent advocacy, but it is not there. You have what happened in Bristol not so long ago, and in Cornwall and Sutton. Lots of money went into recommendations for those reports. What has actually happened? You need to start seeing things from a human rights perspective from a policy point of view so

that, when something goes pear-shaped in a local area, the head of social services knows that it is their head that is on the block.

Advocacy is really important. Advocacy gives people without a voice a voice—an independent person to help them to make choices and decisions that they own; someone independent who is maybe there in a moment of crisis, so that it is not as bad as it could have been because an independent advocate was there to help them to make a choice. You might end up spending £1,000 on an advocacy service that provides independent advocates to a local group of people or, because a crisis has gone wrong, you might end up having to spend £15,000 to put right something that you could have prevented. Advocacy is really important.

**Emily Holzhausen:** I would add to that, from a human rights perspective, that one of the first cases was East Sussex versus a local family—two very severely disabled adult sisters—and the care package was changed. The way they were moved around in the house and to different activities was with a hoist. The girls were not able to communicate very broadly but the family could tell, because they had lived with the girls since they were very small, that they were very distressed by the change and really did not like the change in the way that they were moved. What is so sad is that that case had to appear in the High Court and of course the decision was made in favour of the girls and the parents. But the court had not listened to the parents advocating on behalf of their children; if it had, I think a lot of money could have been saved, the girls would not have had the delay that a court case takes and the parents would not have had the stress of that. What it has given us is an excellent legal precedent, but it grieves me that we have to go through that when common sense really should prevail. That case was centred primarily on the dignity and the human rights of those two young adult women.

**Stephen Lowe:** I would support all the comments. The only thing I would add is that advocacy and support to communicate should be seen as a basic human right and as such it should be seen as a statutory entitlement when people are assessed as being in need of services. Currently advocacy and advice services seem to be seen as something of a luxury item; they are not a statutory entitlement and accordingly they are being cut all over the country at the moment. I think it is important that they are recorded as statutory needs when people are assessed.

**Marc Bush:** I would just echo what everyone else has said, which is that just because something is difficult does not mean that we should not be doing our utmost to try to understand and listen to the voices of all disabled people. I think Andrew is right in putting the emphasis on advocacy; advocacy is the vital infrastructure that we need to take independent living and personalisation forward. It is currently at risk because of the cuts and because of the lack of understanding, particularly among local authorities, about the importance of advocacy in the realisation of personalisation. I think here is a really big opportunity for the Government to look at the work that disabled people's organisations—user-led organisations—are doing in this field and learn from them to understand that everybody's voice can be heard irrespective of the way that they communicate it. That can translate into a service model or a service package that people can have. Some of you may know that this year is the National Year of Speech, Language and Communication, so this is an issue we should be focusing on. Within the convention itself, there is a big emphasis both on alternative and augmentative means of communication and on advocacy provision. Finally I would just say that all the process we have around social care transition planning and health planning should all really have to, as a minimum requirement, take into account everyone's voice and take every action possible to understand the perspective of the individual, including access to independent advocacy.

**Q98 Baroness Campbell of Surbiton:** Andrew, in your written evidence you tell us how important supported housing is for people with learning difficulties and in making independent living an option for more people with learning difficulties. Why is supported housing so important for people with learning difficulties and what are the barriers?

**Andrew Lee:** Living independently is the first step to independence and supported housing is the first step in that. With that in place, confidence can build up and people can then aspire to the next step of independent living, which is employment—a paid job. There is a shortage of supported places, which acts as a barrier for more people with learning difficulties to become independent. Supported housing is a key part of a preventative approach, where crises are prevented and people's skills and confidence are built on.

**Q99 Baroness Campbell of Surbiton:** So you tell us that there is not enough—that it is really, really important to get them on that road to independent living—but you also told us that there is a huge lack of communication between housing associations and local councils and that that is a real problem. Could you explain how this lack of communication gets in the way of independent living?

**Andrew Lee:** As you move on to different services and living independently—for example, out of supported housing to council housing—the services are unwilling or ignorant about making information accessible; even if you know what you want to ask for and you go and ask for it, the people do not know it exists. That can mean that steps towards greater independence are blocked and people's confidence and abilities to make choices are set back. This is because local authorities and housing associations might look on policy documents as if they work together, but the people on the ground—the people whom people with learning difficulties meet in the town hall—do not know; they have not got a

clue what the local authority's policy on what the person is actually asking for is, so they go to a defensive mechanism and say the document does not exist, when you know it does because you have checked it out or found out through an advocacy service or another person that you know. The people who are employed by the council or housing association are disconnected from our world in their day job and that needs to change if our aspirations for independent living, having a job and all the things that we want to do with our lives have a chance to become a reality rather than just something that is in our imagination.

**The Chairman:** We now have two specific questions, one to Mr Lowe and the other to Mr Bush. First of all we have Mr Sharma with a question to Mr Lowe.

**Q100 Mr Sharma:** What contribution do you think the Government's policies on housing are making to older disabled people's access to independent living?

**Stephen Lowe:** The first thing, I think, is that we have not really seen a great expansion in sheltered housing or extra care housing to reduce the need for residential care. I suppose the move away from residential care homes that we have seen with groups such as people with learning disabilities has not happened to older people. I think we need to be doing much more to come up with new ways of providing care and residential accommodation together. That is the main point.

**Q101 Baroness Campbell of Surbiton:** Marc, you say in your written evidence that you are concerned about the potential for regression in promoting independent living for disabled people as a result of recent proposals for reform. Can you tell us what particular proposals you have in mind and how you think they will impact on disabled people's right to independent living? As succinctly as you can.

**Marc Bush:** Yes, I realise that I could spend the next hour on this, so I will try to be very quick. I think there are a number of key areas. If we start perhaps with the reform of Disability Living Allowance, the Government is wiping 20% of the budget out of Disability Living Allowance and at the same time is saying that it is going to better target the benefit. One of the key challenges in doing that is that it is creating a very medical, functional-based assessment, which is trying to see what people can and cannot do. All of the research that has been done internationally, in the UK and by the think tank Demos, has proved that there is very little relationship between the severity of your impairment and the additional costs you face. You can be someone with a learning difficulty or with autism who does not have very complex needs and accesses good services and therefore does not have a lot of costs; equally you could be someone with more complex physical needs who accesses good services and therefore does not have a lot of costs; or you could be someone who does not have good continuity of service and therefore has lots of costs. The problem is that they are going down the same route they went with Work Capability Assessment, which was measuring the distance from work, in looking at someone's impairment and thinking the impairment tells you everything about the individual. It really does not. Disability Living Allowance and Personal Independence Payment is all about promoting impairments and contributing to extra cost. The problem is that, if you do not measure the extra costs that people are incurring, you are not going to target it better so you will end up with the wrong people having the payment at the wrong time. Also, because they are reducing the caseload and reducing the amount of money available for it, they will be cutting whole swathes of people out of the system and will push them ultimately towards poverty and without independent living opportunities, because they just will not have the income.

Linked to that is the closure, as I said, of the Independent Living Fund. The Independent Living Fund was a fantastic resource that enabled people to take on more opportunities to

develop independent living skills and to get access to the services they needed to stay independent and not fall into residential care. That was a really positive step that had been made previously by Government, but phasing out the fund means effectively that a whole group of people who could use a bit of their benefit to access all this support suddenly have all this support that was dedicated to independent living wiped from underneath them.

Finally, I think one of the key areas is, as I also said, the community care grants. Before, disabled people who came across a crisis could access a fund or a grant so they could make adaptations, again to live more independently. Stopping the ring-fencing of this and devolving it to local authorities effectively means that that money will not really be spent on the people who need it most. Again, you push people back into residential care; you push people back into situations where they cannot assert independent living. I think if you look at all of these reforms, including the social care ones and the employment ones we mentioned, there is a really big cumulative impact that will have nothing but a regressive effect on independent living.

**The Chairman:** We have got two questions now from Lord Dubs, the first one to Carers UK and the other one to Scope.

**Q102 Lord Dubs:** Thank you. This first one is for Emily. We know you have specific concerns about the impact of the proposals in the Welfare Reform Bill on the lives of both carers and disabled people who are supported by family and friends. Have your concerns been addressed by the Government during the first stages of the Bill's consideration?

**Emily Holzhausen:** No. Thank you for asking that question, Lord Dubs, because I think it is part of the problem really. They have not been addressed. We were very concerned that there has been no equality impact assessment that includes carers, for example. That is what I was talking about—about disabled people living in the community with different networks

of support with families. I do not understand how we can go through major welfare reform around Disability Living Allowance and not look at how that affects families' principal source of income, which is Carer's Allowance. For those of you who might not be familiar, to get Carer's Allowance you need the middle or higher rate care component of Disability Living Allowance. So we have been told that we have to wait until that assessment is finished, but we have not got a sure timescale nor have we really got any idea of the Government's intentions.

There are other areas. For example, on the benefits cap, anybody with a disability is excluded as long as they meet the correct conditions. If a carer is living in that household, they will not be subject to the benefits cap, but a lot of disabled people do not necessarily live with their family. Again, those carers then will be subject to the benefits cap, without account having been taken of the very important role that they have in supporting their family member to live in the community. I am very concerned about the democratic deficit, if you like, moving through the Welfare Reform Bill and I hope that that will be tested in the Upper House when it comes.

**Q103 Lord Dubs:** Thank you for that. Can you give us an example of how you think that the proposed changes to DLA will impact on disabled people, carers and their families?

**Emily Holzhausen:** Yes, of course. We have difficulty with the medical model as well and have concerns about how the family's contribution and knowledge of their family member will also be counted, because it is shown with Work Capability Assessment that that can be valuable information; otherwise, people are wrongly assessed. The main issue really is not knowing the gateway to carers being able to get their own income using the new benefit, the Personal Independence Payment. If just the higher level of that benefit is taken for care component, thousands of carers will miss out, but how many we do not know and how it

will work in combination we equally do not know. Carer's Allowance might be the lowest benefit of its kind—it might only be worth £55 a week—but it is a vital contribution to people's pension and it is a vital recognition of what people do in the community. So I am concerned on the one hand that disabled people are not being looked at in context and on the other at what will happen to families.

**Q104 Lord Dubs:** If I can continue with that theme, is your principal concern about the proposed cuts to the DLA budget or do you have more substantive objections to the Government's proposed change of approach?

**Emily Holzhausen:** No, the cut to the DLA budget is extremely worrying. The day it was proposed—and, I have to say, launched in the media—we have been inundated and flooded with inquiries from families who are saying, “How will this affect me? What will happen?” They expect the change to happen tomorrow and, because we have no detail, we are spending precious resources and time trying to advise very, very anxious families but not being able to reassure them or indeed help them to plan because we do not know how it will affect them. We have asked Government to be careful about the messages that they put out to the press, in particular messages about people claiming benefits being “scroungers”. I am sure Government would not use that word, but that is certainly how it is being used in the press and families are finding that kind of language extremely demeaning and very negative. These are people who are contributors to society, an important part of our community. I am talking not just about family, but about disabled people. We need to have much more respect than that.

**Q105 Lord Dubs:** Thank you very much. My next question is to Scope—to Marc. You say in your written evidence that the additional costs incurred by disabled people are not

necessarily related to the severity of the impairment. Can you give us some specific examples to illustrate this? What implications do you think this has for assessing eligibility for the new Personal Independence Payment?

**Marc Bush:** Yes, that is broadly what I was mentioning last time I responded. Broadly the Government's proposal of moving to a payment that is around independence was welcomed. It is a really good idea; the idea that you could passport on to greater support that helps reduce cost is a really great example and a really good thing to be following. The problem is that in practice the details do not allow for that. We are not passporting to greater support to reduce extra cost and a lot of the detail effectively means that you will be cutting out people who do incur extra cost but do not necessarily have a high level of impairment. It is all based on the assessment criteria. The assessment criteria, against what the sector and disabled people have suggested, all orientates around your medical impairment, so it would ask you questions about what you can and cannot do when you get up in the morning, when you go to bed and when you are cooking. Some of those things are important in capturing the costs that relate to condition management, but they do not catch all the costs, such as how much you have to pay when you park at a hospital or how much you have to pay because you cannot access particular types of employment. So the sector is calling for a more holistic assessment that will do all of that.

In terms of tangible examples, some people who have talked to us very much value Disability Living Allowance but say, "We do actually have a good continuity of care". They probably will not in the future but they currently do and therefore can use their Disability Living Allowance to help their income go further in terms of their independence. But we also have talked to many disabled people who, in terms of a very medical approach, have a less severe impairment, whatever that means, but actually incur many, many more costs. We know of people who have Asperger's syndrome and who have learning difficulties who face

substantial barriers in travelling independently, making decisions by themselves and going about their community and accessing leisure activities. Those people incur many, many additional costs because of the way that society is structured. Therefore, just because they have a less severe impairment, that does not mean they should be cut out of the system. Actually, they should also have a contribution towards those extra costs. We are in danger here of doing exactly the same thing and not learning lessons from the Work Capability Assessment, which is saying, "If you have got a very severe impairment you cannot do anything, so we will compensate you for that, but if you do not, you know what, you could probably work and you could probably find your way in society". The real picture is much more muddled than that.

**Q106 The Chairman:** To the very last question. Andrew, it is a question for you from Mr Sharma.

**Mr Sharma:** Andrew, you told us that some people with learning difficulties are frightened about the change from Disability Living Allowance to Personal Independence Payment because they do not understand what the Government is planning. What do you think Government or other agencies should be doing to ensure they get the information they need?

**Andrew Lee:** Yes, people are afraid that they may have nothing to live on and that their benefits will be cut. Their fear could be helped by clearer information from Government and the media. There should also be a strong structure of advocacy and self-advocacy groups that support people to access information, but people with disabilities seem right to be afraid of the changes that Government are making. They appear to be restricting who will be able to receive DLA, because of the cuts, down to two categories. They are cutting local

authority budgets and are not ring-fencing social care. The Independent Living Fund has been abolished. Independent living seems to be under attack.

Although more information would be more helpful, it cannot completely address people's fears because it seems that these changes will have a real negative impact. The impression that is given is, "All my benefits are going; I am going to have nothing to live on". That is the impression that people with learning difficulties have. This is about your whole sense of who you are, being able to make choices and having the information; it is about how politicians put messages across. Most people with learning difficulties cannot read or write, so they interpret what politicians say on the news as the absolute truth. It might be twisted here or there for different political audiences, but I know by talking to my members that everybody who is on benefit right now is frightened of having no income at all. That is the impression that people with learning difficulties have right now, because of everything that is happening, what the media are saying and what certain politicians are saying. They might say, "I did not mean it like that; I meant it like this", but this is about how different people interpret what politicians say to their own personal circumstances. If that means that your support goes as well, you are on your own; you have got nothing. People are very frightened and politicians have to do some real soul-searching about how they communicate with people with learning difficulties. We might be a small part of society but we are very, very frightened and you are going to have to do something about that.

**The Chairman:** Thank you very much Andrew and thank you to all the witnesses in this session and the previous session. You have been very clear and very comprehensive in your evidence. There are a number of questions that we were unable to ask you today. We will write to all of you and, if you feel that there are any other issues beyond those questions that we have not covered, please feel free to write to us. Thank you very much.