



**Implementation of the Right of Disabled People to Independent Living
Oral Evidence HC 1074–i–vi**

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Oral Evidence, 24 May 2011, Q 1–37

EVIDENCE SESSION NO. 1. HEARD IN PUBLIC

Members Present

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

Examination of Witnesses

Sue Bott, [National Centre for Independent Living] **Neil Coyle**, [Disability Alliance] **Marije Davidson**, [RADAR] **Jaspal Dhani** [UK Disabled People’s Council] and **Julie Newman** [UK Disabled People’s Council].

Q1 The Chairman: Order, order. Good afternoon and welcome to the Joint Committee on Human Rights on this very first session of our inquiry into independent living. I am very grateful to you all for coming along today. For the record, please introduce yourselves.

Marije Davidson: My name is Marije Davidson from RADAR.

Neil Coyle: Neil Coyle, from Disability Rights.

Sue Bott: Sue Bott, from the National Centre for Independent Living.

Jaspal Dhani: Jaspal Dhani, from the United Kingdom Disabled People’s Council.

Julie Newman: Julie Newman, from the United Kingdom Disabled People’s Council.

Q2 The Chairman: Thank you. Could I make two points at the beginning? First, if you feel that we have not covered all the ground that we wish to—that is quite likely today—I will be asking you at the end that if you wish to submit any additional evidence, we would be delighted to receive it. Secondly, as a Committee, we will be visiting the various groups during the course of our inquiry and will be inviting individual groups to come in to meet us somewhere in London on an informal basis as well.

I want to begin by asking a very straightforward question. We all begin by assuming that you all support independent living as a basis of government policy. Are each of you happy that the present Government share your understanding of what independent living means for disabled people?

Sue Bott: We have moved on a considerable way over the years in government understanding of independent living. We are happy with the progress that has been made, but where we have concerns is on making the understanding of independent living a reality across all government departments. Our feeling is that there is a substantial amount of understanding but perhaps there could be more joined-up thinking on independent living that encompasses the whole of a person's life, rather than just part of it. We feel that where the Government are at the moment is that independent living is often considered to be a matter for one particular department or another, whereas we contend that independent living should concern the whole of Government.

Neil Coyle: Sue has put it very neatly. There is an acceptance of the definition but the problem is in implementation and making sure that the definition is mainstreamed across central government departments in particular.

Q3 Mr Sharma: You welcome the emphasis in the current policy on placing more purchasing power in the hands of disabled people but are concerned that there are other impediments within the wider system that are getting in the way of a more demand-led cost-effective system. Can you explain what this improved system would look like and what the impediments are that stand in its way? What can be done to remove them?

Sue Bott: What we see as the impediments to full involvement are, first, that not all the access considerations are always taken into account. Sometimes there can be an assumption that disabled people will pick up information in ways that the rest of the population is expected to—increasingly regarding the use of the internet, for example. This is not just a problem where disabled people are concerned but it has a particular impact on them. Not all the access needs are met. We cannot all use the internet, either because our impairments do not allow us to access it or because we know that disabled people are not as economically advantaged as other sections of the population. In that way, we feel that disabled people often miss out and are unable to respond to things like government consultations.

Jaspal Dhani: I should like to add to that in terms of the vision, and identifying and overcoming obstacles, as per Article 4 of the UN Convention on the Rights of People with Disabilities. Paragraph 3 in particular speaks very much about consultation and engagement of disabled people. We believe that in developing services that support the needs of disabled people at an individual level and at a community level, consultation and engagement are key to the future success of any policy. We certainly see that as part of the vision, going forward.

Marije Davidson: At the moment, there is a barrier, and the disability policy makes it very clear to people that that duty still exists under the public sector equality duty. That has recently been confirmed in the Birmingham judgment about social care cuts. The judge made it very clear that it is important actively to go out to disabled people and other people, give clear information about what the proposals are and listen to disabled people. Unfortunately, we still find that quite a lot of decisions are made without talking to disabled people, and that leads to bad decision-making. A lot of cost in the system is caused simply by not talking to disabled people and user-led organisations, and that is a major impediment.

The Chairman: If colleagues wish a particular organisation to address particular questions, please indicate that.

Q4 Baroness Campbell of Surbiton: I want to come back on the duty to involve. I believe that the duty has recently been diluted somewhat. How well has a duty to involve worked over the past two or three years? What worries do you have about that change? Have there been any indications of sliding backwards on that duty in terms of evidence?

Marije Davidson: There has certainly been progress. This week there was a report looking at the progress that has been made on the equality duty. There certainly has been involvement for disabled people and disability groups at an early enough date, before decisions are made. We have heard that there has been sliding back in recent months and, maybe ironically, it is on the equality duty. In January, the Government published proposals for specific duties which set out that public authorities should meet the general equality duty. That was after a long consultation. It was a good consultation, and we were quite happy with the outcome. Then in March, they suddenly announced the policy and reduced the proposals quite drastically. Basically, our duty is to report on what the public authority has done in the past rather than on what it is going to do in the future. We are quite concerned that, if that is the way to involve disabled people, public authorities listen to us. I am really concerned that slipping back is happening.

Neil Coyle: It seems clear to us that the involvement of disabled people has never been successfully delivered, particularly at local level. The Birmingham case just last week probably emphasises that because, had disabled people been involved and engaged and so on in what councils were proposing to do with care services, it would have been immediately apparent that there was a threat to equality of opportunity. The problem now is that, rather than looking to confirm the need for the duty and enforce it, organisations such as the Equality and Human Rights Commission and the Care Quality Commission are seeing their roles or responsibilities reduced, and the Equality Act seems to be seen as a bureaucratic burden rather than as being integral to delivering services in support of disabled people.

Q5 Lord Dubs: My two questions are essentially to the DRP, I believe. You have told us that there is a gap between policy aspirations in the UK and the everyday experiences of disabled people. Can you give us some concrete examples of how you think national policy commitments on independent living do not filter through to disabled people's everyday experiences?

Marije Davidson: You could look, for instance, at the current Government's commitment to give £2 billion extra to social care support through the local authority. If people then find that a lot of social care is being cut in, for instance, Birmingham, that is one practical example. The previous Government's commitment to have user-led organisations in every locality by 2010—last year—has not been realised. Now we hear about user-led organisations closing in the country. Those are two very concrete examples.

Jaspal Dhani: I should like to add that the Government's decision to cut the Independent Living Fund in the future will, we feel, have some brutal consequences for many disabled people who rely on direct payment support and who therefore need access to the additional money afforded through the Independent Living Fund. The brutal outcome is that many disabled people will lose the level of support that they need to remain independent in the community, thereby putting their health and well-being at further risk. Likewise, we feel that the planned changes to the disability living allowance, particularly the care component for individuals residing in care homes, will also have a negative impact on people's independence, as it is likely to leave such individuals isolated within their care homes and dependent on organised activity. It is taking away the freedom and mobility that non-disabled people enjoy as and when they wish, whereas individuals in care homes will be returning to a life of isolation.

Lord Lester of Herne Hill: I think that Mr Coyle said that the powers and duties of the Equality and Human Rights Commission were being weakened, as were the commitments under the Equality Act. Would it be possible to write to us with chapter and verse explaining exactly what is meant on both those important points?

Q6 Lord Dubs: This question is also primarily for the Disability Rights Partnership. In your written evidence, you talk about a need for a new robust policy framework. How would the current independent living strategy need to be changed to provide for such a framework?

Sue Bott: The first thing to say would be that in discussions that we have had with the Minister responsible for the independent living strategy, as we understand it, there has been no decision yet on how the strategy should be moved forward, if indeed it should. We suggest that a way forward is to take a look at the independent living strategy, which was a five-year strategy and has not yet been completed, and look at how it can be completed. For example, some of the outstanding work of the strategy is looking at the economic position of disabled people. As we understand it, when the strategy was launched in March 2008 it commanded all-party support. We know that, of course, the Government have been exercised by many things since the general election, understandably, but we would hope that the independent living strategy could be looked at and completed as a cross-departmental piece of work. That would be extremely helpful in raising the issues of independent living across Government, which we sense have been forgotten about in all the business that needs to take place. We would like to see more focus on them.

Q7 Baroness Stowell of Beeston: Hello. My name is Tina Stowell. I have two questions. The first is aimed at the UK Disabled People's Council. In your submission, you said that the impact of the Government's proposals to reform the benefit system, together with cuts to funding, will lead to a breach of Article 19 of the UN Convention. Can you explain your conclusion, and is there a particular proposal which you think will violate the convention?

Jaspal Dhani: We feel that the reduction in support provided to individuals and organisations will lead to the non-fulfilment of Article 19, as my colleagues have already highlighted. The impact of the removal of funding is leading to a reduction in services, in the autonomy that individuals can exercise over their lives, and in their representation. Article 19 talks specifically about opportunities for people to choose where they live and how they live and, in particular, how they enjoy their day-to-day life. If we take the issue of capping housing benefit as an example, it will lead to disabled people not being able to afford their current accommodation and therefore not being able to exercise their choice of living where they want to live, which can also impact on the ability to keep their jobs, because it can be impossible or difficult to travel from one location to another, particularly if their support services are not there. Given the state of inaccessible transport that many disabled people have to face, that leads to a greater level of isolation.

When we talk about independent living, and look at the level of support afforded to people who have been assessed by social services as needing care in the home, those services are also being reduced. The removal of the independent living fund, for example, creates an extra burden on disabled people and on the budgets at local authority level. Local authorities are already starting to reassess, in many cases, individuals who are already in receipt of direct payments and have started to move the qualifying criteria. Some local authorities will fund only those individuals who are deemed to have critical support needs, which means that others who are outside that assessment may lose out on the support that they would otherwise have obtained.

We feel that when we look at those issues in a holistic manner, it potentially contravenes Article 19.

Neil Coyle: I would like to add a few more concrete examples of what is happening right now and what the government proposals would mean. We have the work capability assessment being used to move people off incapacity benefits. The test is so poorly

implemented that 40% of the people who appeal are successful in overturning the assessment decision.

Q8 Baroness Stowell of Beeston: Is that 40% of disabled people or 40% of all people?

Neil Coyle: If they are people who are moving from being determined as fully fit to work into an employment support allowance category, it is likely that they would meet the DDA definition of disability. Anyone able to access employment support allowance, because of the points system that is allocated in order to get into it, would meet the legal definition. So these are disabled people who are being found fully fit for work and having benefits and support reduced—the support to find and get to work. There is one example.

Another concrete example is the proposed time-limiting of contributory ESA to one year for those in the work-related activity group, which will see 400,000 people with health conditions and significant impairments losing support after one year, despite the evidence suggesting that only 13% of disabled people were able to find work within a year under Pathways to Work.

There is a risk that the new assessment for the personal independence payment, which is replacing DLA, will generate a perverse incentive for disabled people not to use aids and adaptation. If you are not using aids and adaptation in order to secure a small amount more financial help, it is unlikely that you will be able to live independently and be included in the community, so arguably there is a case there as well. We have already had mention of the loss of mobility support for disabled people in care homes. Losing mobility support to get out into the community to do anything—visit family, go shopping, even attend a GP—is a likely outcome of cutting 78,000 people from that particular bit of support.

There is also a more general point around the government narrative for this, about tackling a lifestyle choice. Many of us would not accept that anyway, but it acts as a disincentive to employers to take on disabled people who are being shifted within the benefits system and, arguably, increases the stigma and discrimination that disabled people experience in daily life. It is quite worrying that Scope's ComRes study suggested that 37% of disabled people believe that the attitudes towards them have got worse in the past year.

Q9 Baroness Stowell of Beeston: I was going to direct my next question towards the Disability Rights Partnership representatives. I think that you have kind of answered it, but let me just tell you what it is, and if you want you can give me a brief response, because I am conscious that we have lots to get through. You all agree that it is important to take a holistic approach to decision-making on policies that affect disabled people's lives and to assess the cumulative impact of policy changes. Can you give us a concrete example of the cumulative impact of recent policy changes? I think that you have kind of covered that, but you may want to say something briefly to encapsulate what you have covered.

Sue Bott: I liken support for disabled people to a house of cards. If you remove one card, a whole lot of cards collapse. A good example of that is the decision to close the Independent Living Fund. Nothing has come in to fill that gap. We presented evidence to you of specific cases. I am thinking of a particular case that we highlighted of a lady in Nottingham who, by the time she had got her social care package, found that she could not complete the process. She was going to put in an application to the ILF, but she found that it had closed. Unfortunately, her local authority is not in a position to make up the funding that she would have got, had she been able to apply to the ILF.

The result is that yes, the local authorities are still contributing the amount of support that they originally agreed but because the ILF part of the support is missing and the local authority cannot meet that support itself, her life is very restricted. All she can do is just

about maintain herself in her own home. She certainly cannot think about getting out of her own home and doing anything in the community.

That bears out what I was saying earlier, that there needs to be joined-up thinking across Government. When one government department makes a decision to take some action on one of its responsibilities, in this case the DWP on the ILF, there is an impact across Government as far as disabled people are concerned. I remember that when this subject was first introduced to us by DWP civil servants, they said, “Independent living is not really our responsibility; it’s the Department of Health’s”. I said, “No, actually, independent living goes across Government”. This is a classic example of where things go wrong. Once one of those cards is pulled away, life for a disabled individual can deteriorate very rapidly. I am sorry, that was not a quick response but I hope that I explained where we are trying to come from.

Neil Coyle: If I can chip in as well, the Home Secretary's letter to the Chancellor of the Exchequer outlining the fact that disabled people would be disproportionately affected, by the Budget decisions in particular, exemplifies the point. But Demos has estimated that there will be £9 billion lost in income by disabled people within this Parliament. That comes partly from 400,000 people losing employment support allowance. It could potentially come from up to 652,000 working-age people who are currently receiving low-rate care DLA, when that bit will not be replaced in the personal independence payment. We have already talked about the 78,000 care home residents and touched on the social care charges and changes to eligibility points as well, with some disabled people in Lincolnshire experiencing 98% increases in weekly charges. In Derby City it is something like 78% in its hourly rate charges. Those are direct results of councils making changes from government policy.

More generally, I believe the NCVO are logging organisations affected by cuts as well. Of the 500, I think that more than 50% are involved specifically with disabled people, adult social care, mental health and other volunteering responsibilities which would support disabled people normally. The cumulative effect is massive for thousands of disabled people and their families.

Marije Davidson: There is a certain tendency to keep support for those who are most in need of it—those who are very disabled. We like at present to talk about the most vulnerable and the people most in need of support. There is a risk that there is a gap between people who do not need support and people who need loads of support. In between there are many people who need some degree of support, but no one is supporting them. We are talking about the right to independent living. This is a clear infringement of the right to independent living. However, the right to independent living is a very positive duty. It is about enabling people to participate in society, to have social interaction and to work. I am concerned that by focusing just on people most in need, we are starting to talk about the right to life of people who will die without support. We are talking about the right to be free from being subjected to inhumane and degrading treatment. I am worried that there is this narrowing of focus on civil rights, whereas the right to independent living is much more positive. It is about enabling people to go out and about and contribute to society.

Q10 Lord Lester of Herne Hill: I am not an expert in any of this. I am in no position to evaluate the social facts that have been presented to us. However, it would be helpful to know whether the witnesses agree with the stated aims of the Government so far as their independent living strategy is concerned—the aims for their five-year programme.

Is the argument about those aims or about whether they are being properly implemented? Or is the quarrel not with implementation but with the stated aims themselves? That is, all disabled people ought to have the same choice, control and freedom as everyone else; support is to be based on their own choices and aspirations; and the outcomes are to be

measured under the three main categories. Is the quarrel with those aims or with the implementation of those aims?

Sue Bott: The aims are fully supported by our organisations. Indeed, the independent living strategy itself was launched at the offices of NCIL and we very much endorse those aims. As I have said, we believe that the aims are supported across the political spectrum, so our concern, as you rightly say, is about their implementation and the fact that, as far as we are aware, the independent living strategy is currently lying in someone's in-tray waiting for a decision about whether it will be picked up and further work done on it.

Q11 Rehman Chishti: The question I want to ask has already been alluded to by Mr Dhani. Concerns have been raised by all about the changes that have been made to the independent living fund grant. That being the case, where is the evidence to support your concerns about the effect that will have on independent living?

Sue Bott: Can you clarify a point? Are you talking about the independent living fund rather than disability living allowance?

Rehman Chishti: Perhaps I can make it clear. This is not about one specific example, but about the wider evidence. It is not about one specific issue, but the overall evidence from different corners of society which is saying, "This is the impact it will have".

Sue Bott: We have to recognise that the fund was closed in October, so it is rather early days in terms of being able to assess the impact. Nevertheless, I have presented to the Committee two cases involving the independent living fund where disabled people who would previously have received funding are now facing a funding shortfall. That has an impact on their lives. We were given to believe last summer that there would be a period of consultation on the independent living fund, so we were quite surprised when the decision to close the fund was announced.

I would just reiterate that when these decisions are made, their full impact needs to be taken into account. It seems to us that the fund was closed on the assumption that local authorities would make up the shortfall caused by its closure. If we listen to the reaction of bodies like the Association of Directors of Adult Social Services, we hear them say, "We simply have not got the money to make up the shortfall". This is a problem that will grow and grow. At the moment, it is a problem for people who would have applied to the fund previously and now cannot do so, but in the future, when the fund comes to its full conclusion, it will be a problem not only for all those people who have accumulated up to 2015 and who would have applied to the fund, but also for the 21,000 existing recipients. That is because to date there has been no suggestion about where that money can come from.

Q12 Rehman Chishti: Can I clarify one thing? You said 21,000, and you said you had the example of two who would be affected by the changes. Am I right in thinking—correct me if I am wrong—that out of 21,000 people who are claimants, that is the figure at which the Government stop? You have only two examples.

Sue Bott: I think that there is a misunderstanding here. I have presented two examples to you. I could present a number of other examples to you and I would be happy to do so, but I am mindful of how much reading matter you have. But the point is that those two are examples of people who have been affected by the closure of the fund since October last year, so they are people who would have been able to apply for the fund had it continued. It is closed to new applicants; that is probably where we are getting confused. A decision has been taken that the fund will close in its entirety, and it is at that point that the 21,000 people who currently rely on that fund will find that they do not have that funding any longer, and to date we have no clear indication of where that funding will be made up from.

Q13 Lord Morris of Handsworth: I also want to explore a deeper understanding about some of the concerns that have been expressed by different groups. In this instance, it is the United Kingdom's Disabled People's Council, which recently organised a very high-profile march, focusing on the impact of cuts and changes to the benefit system for disabled people in the Welfare Reform Bill. Is there a particular provision in that Bill which you think will impede independent living in a way that breaches the UN Convention, or is your main concern the aim to reduce the budget for disability allowance by 20%?

Julie Newman: One of our major concerns is that it has already been recognised by the Government that disabled people suffer significantly from poverty; it has also been recognised by the Government in the wider arena that the amount of money that we need to enjoy or exercise independent living needs to be safeguarded. The impact of economic management that the current Government are having to face is going to have a significantly disproportionate impact on disabled people, and that was the focus of the campaign and continues to be so. That is being evidenced by the range of partners who took part in that rally and lobby of Parliament. It is interesting that there is almost unanimous agreement across a range of organisations that historically do not usually agree with each other. But whatever the focus for their work of the disability charities providing services for disabled people, when they are in dialogue with the people receiving those services, as we are, the impact is disproportionate. Say for example there is a cutback to access to work; that impacts on our opportunities for continued employment in a way that would not apply for someone who was not reliant on support services to continue to help us. Similarly, with disability living allowance, one of the negative impacts of the current economic climate on people receiving the mobility component of the disability living allowance is the fact that petrol has more or less doubled in cost, and there has been no recognition of increases in the cost of going from A to B. For some of us who rely completely on our cars, which are provided through government schemes, we still have to meet twice what we were originally paying out three years ago in order to get from A to B. The whole thing is disproportionate, and that is what we wish to emphasise.

Q14 Lord Morris of Handsworth: Perhaps I may ask a supplementary question, because it is important that we have the widest and clearest understanding of the issues and of the reasons for your march, for example. Is there a particular provision on disabled people in the Welfare Reform Bill that would, in your view, impede independent living in a way that breaches the UN convention?

Julie Newman: If anything impedes independent living, it is in breach of the UN convention; that is the bottom line. One of the significant difficulties that we have with the Bill is the active consultation. We do not believe that there is an active and fully inclusive consultation with disabled people, and that immediately puts us in breach. We can identify specific areas and submit them formally in writing; we would be happy to do so. The key issue is lack of active consultation.

Neil Coyle: There are specific proposals. We have touched on scrapping mobility support for disabled people living in care homes, which prevents inclusion in the broader community. The axing after one year of employment support allowance for people in the work-related activity group presents a further financial barrier and certainly does not promote equality of opportunity. The abolition of the disability living allowance is also an issue. The DLA was the original personal budget, the original extra help to cover the additional costs of living with a disability. It was introduced in 1990 under Margaret Thatcher and was a key means of supporting independent living for thousands of disabled people. The disproportionate and targeted prevention of independent living and inclusion that the Welfare Reform Bill's cumulative effect will produce comes combined with a narrative that somehow the disabled

people receiving the support are faking, or are not entitled to it, so that it should be targeted elsewhere. A key example of how independent living just is not factored in to the Welfare Reform Bill is the complete failure not just to evolve but to provide impact assessments and an analysis of the numbers of disabled people who will be affected and what the outcome will be.

Q15 Lord Morris of Handsworth: Is it possible for you to give the Committee a note on where the Bill, in your judgment, specifically breaches the UN Convention?

Neil Coyle: Absolutely.

Q16 Baroness Campbell of Surbiton: I apologise to the Committee; in my supplementary question, I did not declare my interests. I will do so now—if you have an hour to spare. I am the trustee and co-founder of the National Centre for Independent Living. I am also the chair of the Government’s Rights Control Advisory Group. I am co-chair of the All-Party Parliamentary Disability Group. I am a personal recipient of the disability living allowance and community care direct payments. Until December last year, I was chair of the Government’s Independent Living Scrutiny Group. I think that that is all—but, like when you get married, if anybody knows any interests that I have left out, please feel free to speak out.

I particularly want to ask about safeguards and safeguarding. I want to focus again on human rights, violations of human rights and why Article 19 might not be safeguarded in the way that you might want. In your evidence—this is a DRP question—you said that some of the duties and obligations that protect and support disabled people are under threat: for example, from the red tape challenge organised recently by the Cabinet Office. Could you give examples of safeguards that are essential to independent living and why they should not be subject to this red tape review? We have already touched on the duty to involve; can you give examples of others?

Marije Davidson: The red tape challenge is a very broad review of different pieces of regulation. They are now looking at health and safety and in June they will be looking at equality. In July and August they will be looking at social care. They will be asking the wider public for their views on the regulations and, in the case of equality, also at the primary legislation. The equality duty remains an important safeguard. However, the Equality and Human Rights Commission, as a body, does not protect us. The Equality and Human Rights Commission is currently conducting an inquiry into disability hate crime and disability-related harassment; it is partly scrutiny of relations in society and partly about what public bodies should do to protect disabled people. That is a very fundamental part of independent living—disabled people’s ability to live free of fear and feeling secure. Having a body like that, which checks on the state of the nation and intervenes when something goes wrong but also actively promotes equality, is a very important safeguard. I provide a note to the Committee, as Lord Lester requested.

Another safeguard is the role of user-led organisations locally and nationally, but mainly locally, and their ability to communicate with local authority decision makers and make sure that the right decisions are made; to make sure that if there is an adverse impact then steps are identified to make sure that does not happen.

Jaspal Dhani: I will just add to that. We feel that the planned cuts to services like legal aid will also have an adverse effect on disabled people and their ability to exercise their rights. Where disabled people feel they have been discriminated against by having welfare benefits removed, services reduced or access to employment infringed, we are not really quite sure where they will turn to get the level of support that they will need for legal representation. In the past, that has been available through legal aid and also through HIC, for example. The

concern is that disabled people not only stand to have their rights reduced but also the resources available to them to exercise those rights are likely to be reduced as well.

Neil Coyle: It is impossible to have an ability to live independently and be included in the community if employers, education establishments and others do not know what to do in order to make it possible for the disabled to live independently, so here the Equality Act, the reasonable adjustment provisions and the role of the Equality and Human Rights Commission are absolutely key. Without those bodies and without that support in terms of practice development at the Equality and Human Rights Commission, for example, it is impossible for other people in society to know what they need to do in order for disabled people's living independently to be included.

Q17 Lord Lester of Herne Hill: Is not the fundamental problem about the red tape challenge that all the safeguards in the Equality Act are essential and that, at a time when one is trying to promote a culture of support for the equality agenda, to suggest that the thing might be scrapped or an example of overregulation creates problems? One is talking about fundamentals rather than technicalities.

Marije Davidson: That is absolutely true. If you talk about the red tape challenge, equality and support seems something that costs money. Actually, inequality costs an awful lot of money. You talk about an enormous pool of talent wasted. You talk about people who cannot work or mostly cannot work because of the attitudes of others and the barriers that are there. It is about independent living—people being able to participate if you do not have equality. If the barriers like attitudes, physical bars and communication are not broken down, then how can you expect people to participate? That is absolutely right. The Equality Act has been the product of many years of people bringing case law built on the experiences of people feeling imprisoned. It is absolutely right to keep the belief and promote it rather than say, “It is too hard”. No, it helps everybody, the Disability Discrimination Act 1995. Now, many employers know what they have to do. They may not always do what they are supposed to do, but they know that there is no reason for that. Trains are much more accessible; they need to be more accessible. Healthcare is more accessible. It saves money.

Q18 The Chairman: Mr Coyle, are you going to quote Oscar Wilde for us—his definition of “philistine”: someone “who knows the price of everything and the value of nothing”?

Neil Coyle: I was not intending to; thanks for the comment. It is really important to remember where we are at right now, which is that a third of disabled people still live in poverty. Half of disabled working-age adults are not in employment. Those barriers need tackling. The Equality Act helps tackle those issues. If we want to generate a society where disabled people are more capable of self-managing, if you like, the Equality Act is absolutely essential to delivering that. To suggest otherwise is deeply offensive for the thousands of disabled people who campaigned for decades to get any kind of disability discrimination Act introduced in the first place.

Q19 Lord Bowness: I fear that this question has probably been answered, but it applies particularly to Mr Chishti's question, when you referred to lack of consultation. At an earlier meeting, Members asked Ministers whether the Government had conducted impact assessments relating to their obligations under the convention when introducing changes to the disability living allowance. The Minister for Human Rights said that public expenditure decisions have to be taken and, of course, that the department will keep an eye on anything that would look like a flagrant disregard for human rights. The Equality and Human Rights Commission has accepted that it cannot at present advise on the likely impact of the Government's proposed changes, but calls on us to press the Government for information

on cumulative impacts. Other than consultation, is there anything that the Government can really do to assess in advance the impact of policy changes on independent living or compliance with the UN convention? Perhaps I may ask a follow-up question at the same time. Are you satisfied that the Government are taking adequate steps to monitor the impact of policy changes and cuts to funding, including the impact of changes made by local authorities? If the answers to all those questions are no, what is the answer? What should they do?

Sue Bott: One of the problems is that policy changes have been introduced too quickly and have not really been adequately thought through to the end. The consultation on the disability living allowance and its replacement by PIP is a classic example. I remember thinking, when I read the consultation document, “I don’t know how on earth I’m supposed to comment on this in any great detail”, because what is being put forward in the consultation document does not really tell me, other than that we will have this benefit called personal independence payment, how that will work out on a day-to-day basis. It would be extremely difficult for the civil servants then to go away and do some kind of impact assessment. Critical to the new benefit is how it will be assessed and who will be eligible for the new benefit. It is not really until you know the answer to that question that you can really assess what the impact will be. We have rather a bizarre situation where a major change is being proposed in the Welfare Reform Bill without any detailed information behind it. No one can have much of a clue about what the total income impact will be. We can only surmise what it will be; and the only really known factor that we have is George Osborne announcing in his Budget speech last June that DLA—which, incidentally, he grouped as an out-of-work benefit; but, of course, it is not—would be cut by 20 per cent. That seems to be a very strange way to approach policy decisions. You have to understand why policy is there in the first place and work out what you are going to replace it with. Then you know what the impact is going to be.

The Chairman: We are very conscious of time. I apologise. We have one big question left, and then I will ask you to write to us with your concerns about the issues that we may not have covered today. We will also ask you a series of questions that we have not been able to address today.

Q20 Lord Dubs: So far, a great deal of emphasis has been about money and cuts, and so on. 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. The Government stress that independent living is not just about money. Do you agree with the Government’s assessment that meeting the obligations of the UN convention is not just about money?

Julie Newman: I would really welcome an opportunity to respond immediately by saying that one of the areas of discomfort that UKDPC has had in relation to this hearing and to the wider dialogue is that when we refer to the convention we seem to have lost the language of rights. The question that was asked previously about ensuring that the convention is effectively implemented must hinge on rights. I strongly advise that we go back to a dialogue about rights and the use of the justice system, if necessary, to ensure that that is upheld.

Neil Coyle: There are means of delivering greater independence at reduced cost. I know that portability of care assessment across the country is close to the heart of one of your Members here today, but routinely tackling overassessment would be beneficial and would save money. But contrary to that, we are going to have a personal independence payment assessment at £675 million, which may require deaf-blind people to turn up for a regular review even without there being a change in their circumstances. There is existing evidence

of other cost benefits to be derived, particularly in the long term, by supporting people through early intervention. For example, there is the ODI's *Better Outcomes, Lower Costs* report and the Audit Commission has done work on this. There is a wealth of evidence. At the same time the Government is moving to a situation in welfare reform whereby disabled people moving into work is guaranteed, if you like, in terms of how the Government is changing its expenditure. We are not seeing that level of investment in social care despite the fact that there are growing costs from carers not being able to go into work, resulting in people not being supported, so that there are downstream costs, if you like, of failing to meet needs now which investing in independent living would help to resolve. There is a broader point there around the cuts narrative. It is almost as if it is being suggested that you can just take this money away and it will not have any impact. That links back to the previous question. We know what cutting DLA might mean because we know where DLA is spent. Disabled people have been surveyed for years on what they use it for. Some of it is spent on prescriptions, some on accessible transport. If you start peeling that support away, the impact is quite clear. There are downstream costs for the health service that we think will be quite considerable. Coming back to the rights point, we know from Disability Alliance research that disabled people are saying that without some of the support that is being peeled away, they will question the value of continuing to live. Those costs need to be taken into account as well.

The Chairman: Thank you very much. Thank you all for coming along today. On behalf of the Committee, I thank all of you who have given us written evidence and remind you that we will be writing to you to ask specific questions but we may not cover all the issues that you wish us to cover. Please add particular issues into any memorandum. For example, I have picked up the very central question of rights. I would also add into that the whole impact of devolution and localism. I am very conscious of the fact that rights are universal and that the whole ethos and strategy of localism and devolution may well cut across that. Could I also ask you to reflect on the fact that there is no specific Minister dealing with independent living as such? You might wish to suggest—I have not seen this yet in any written evidence—that there ought to be a lead Minister with cross-cutting responsibilities. However, I may be speaking out of turn there. Perhaps somebody has written about it. Thank you very much and have a safe journey home. I now ask the next witnesses to come forward.

Examination of Witnesses

Jim Elder-Woodward, [Independent Living in Scotland] **Pam Duncan**, [Independent Living in Scotland] **Rhian Davies**, [Disability Wales] and **Paul Swann** [Disability Wales].

Q21 The Chairman: Good afternoon. For the record, could you please introduce yourselves?

Paul Swann: My name is Paul Swann. I am the independent living policy officer with Disability Wales.

Rhian Davies: I am Rhian Davies. I am the chief executive of Disability Wales.

Pam Duncan: My name is Pam Duncan. I am policy officer for the Independent Living in Scotland project.

Jim Elder Woodward: My name is Jim Elder Woodward. I am the convenor of the steering group responsible for the Independent Living in Scotland project's direction. May I ask the Committee, if they do not understand what I am saying, please indicate and my colleague will interpret.

Q22 The Chairman: For the record, we were due to have witnesses from Northern Ireland. As most of you know, they were unable to travel because of the volcano in Iceland. As with the previous witnesses, we assume that you all support independent living as a basis of government policy, but are you all happy that the UK Government and each of your devolved Administrations or Governments share your understanding of what independent living means for disabled people?

Rhian Davies: Disability Wales fully supports independent living. We have been campaigning for some time for a national strategy on independent living in Wales. An issue for us is that Wales appears to be the only country in the UK that does not have a specific overarching strategy on independent living. We feel that that is a huge loss for disabled people in Wales. We have been working away, lobbying, campaigning with the Welsh Government and other bodies to secure the introduction of an independent living strategy.

Pam Duncan: In Scotland we have a very specific approach to independent living. The independent living movement's definition of independent living is that disabled people of all ages have the same freedom, choice, dignity and control as other citizens at home, at work and in the community. We then go on to say that it does not mean living by yourself or fending for yourself; it means rights to practical assistance and support to participate in society and live an ordinary life. We already have that in our submission so I did not just read it out for no reason. The issue of practical support to live your life with freedom, choice, dignity and control is central to the way that we view independent living. In Scotland we have a shared approach to that vision. If you wanted to download the whole vision on independent living in Scotland, you could see it on our website. We share that vision with the Convention of Scottish Local Authorities, the Scottish Government and the disabled people's movement in Scotland.

However, we have some concerns about the shared understanding. We believe that there is considerable patchy provision, not just across government directorates, but between central government and local government. We also feel that the buy-in towards independent living relies heavily on strong leadership. So we are not sure about the buy-in below strategic level. I am sure you will be aware of the concordat in Scotland, which presents some issues and challenges for independent living in Scotland, because very often there is a difference between what central government think and suggest and what local government then consequently do. The concordat is there in the middle.

In the UK as a whole, we are concerned that, although the Government recognise in rhetoric that they share the definition, some of the approaches to independent living and to disabled people that we have seen recently—for example, within welfare reform there are cuts to DLA and the closure of the independent living fund—represent a strong focus on retrenchment. We do not feel that that supports independent living. We also feel that for independent living to be a reality, collective co-production is essential, and strengthening the voice of disabled people and their organisations to challenge decisions and oppression, which you have already heard about earlier this afternoon, is crucial. We are not sure that that has translated into what we have seen in recent months.

Q23 The Chairman: I take it that there is a dialogue between Wales and Scotland and that you would wish to encourage that dialogue, given the differences between Wales and Scotland.

Rhian Davies: Yes. I know that there have been joint meetings between Wales and Scotland. In our discussions with the Welsh Government we have promoted particularly what has been going on in Scotland, because there is perhaps a greater feeling of affinity with the Scottish approach to independent living, compared to England. The stumbling block for Ministers in Wales is that the model adopted around independent living in England focuses on personalisation, which politicians in Wales see as privatisation by the back door. In Wales we are particularly committed to the ethos of public services and there is huge concern about dismantling of the welfare state, social services and the NHS and so on. That has been a particular challenge for us.

We presented a manifesto calling for a national strategy for independent living ahead of the recent Assembly elections. We have adopted our own definition of independent living, which is that it “enables us as disabled people to achieve our own goals and live our own lives in the way that we choose for ourselves”. We have been promoting that with the Assembly in the absence of its having its own understanding of independent living, I would contend. Recently the Assembly introduced the social care charging measure, which addressed the postcode lottery of charging in Wales. In the guidance produced for local authorities, we put forward our definition of independent living. That was picked up by the Assembly, so I guess that we are inching towards the door, but we recognise that we still have a long way to go on encouraging the Assembly to be proactive on this issue.

Q24 Mike Crockart: To a certain extent, the question that I was going to ask has been answered by what you have said already. I address this first to Independent Living Scotland: you have suggested that although the policies in Scotland are good on paper—you have certainly given a clear statement of what that vision is—there is a gap between policy and the experiences of disabled people. You have talked about one thing that points towards how that gap could potentially be closed in strengthening the voice of disabled people. Are there other concrete things that you think could be done to try to close that gap?

Pam Duncan: I think that there are several things that could be done. First, there should be a real focus on rights and on human rights in the United Nations Convention. We also believe that the issue of localism has presented some huge challenges to independent living. Often, localism is seen as debate between central government and local government, but in fact we see the difficulty as being the difference between localism and human rights. Recently we had a discussion on the issue of portability, which the Committee will be fairly well attuned to, and the issue of localism is particularly pertinent there. When one local authority can make very specific decisions on care and support in that area, it can then become a barrier when trying to move either to or from it as a result of that. It was defined by our colleagues in COSLA as the difference between legitimate localism, which looks at

developing local people's ability to coproduce local community decisions that are suitable for that community, and illegitimate localism, which goes head to head with the human rights of disabled people. We suggest that addressing some of those intricate issues of localism is crucial.

We also believe that a lot of policy translating on the ground, and from the UK Government, focuses very much on raising thresholds in the economic situation that we find ourselves in. We believe that we need to have a stronger focus on prevention so that we recognise that empowering disabled people is the way, in order that they can contribute as equal citizens in society, rather than raising thresholds. For example, across the board we are seeing eligibility criteria rising to the point where you get life and limb support. In fact, that, coupled with the cuts to the independent living fund, means that people are essentially imprisoned in their own homes. We do not believe that that approach is necessary; in fact we consider it to be economic suicide if we do not take a preventative approach and consider that disabled people should be able to live in society with freedom, choice, dignity and control as others do.

Q25 Mike Crockart: I turn to Disability Wales. You have already said that the problem there is not so much the gap between policy and implementation but the lack of policy. Privatisation by the back door is something that I understand from the Scottish perspective; it is certainly a major barrier to overcome. How do you see movement towards overcoming that barrier so that people understand that it is more about personalising rather than privatising?

Rhian Davies: To be honest, the very fact of being here today is a huge opportunity for us to present our case on the need for an independent living strategy in Wales. It is extremely embarrassing to us that in the draft report on the progress of the UN Convention on the Rights of People with Disabilities, in the Article 19 part, Wales has no section on what it is doing around independent living. I hope at least that the message is going back down the M4 that we urgently need to address this issue.

The issue in Wales is that the approach has tended to be focused on particular impairment groups—we have an older people strategy and we have had strategies around people's learning difficulties and mental health—so the view is very focused on people's specific impairments. There is no overarching sense of a right to be able to live independently in the community, whatever your impairment and whatever characteristic you might have. Other issues that Wales has taken forward have tended to be fragmented.

One of the challenges that we face is that the whole debate on independent living is seen to be one of social care, not of rights. An example of that is that when we put forward our petition to the Assembly last year calling for a national strategy, the petitions committee referred it to the Minister for Social Services in the Welsh Assembly Government, not the Minister for Social Justice and Equality. We are really at the starting blocks.

The Assembly would say that it has a commitment to direct payments, but it is very patchy in Wales. Take-up is very low and depends on individuals championing it at the local authority level. Disability Wales did some research on accessible housing registers in Wales, which we know make a huge impact on looking what accessible housing stock exists in an area. We discovered that just 10 of 22 local authorities have an accessible housing register. On transport, there is a strong commitment to access to rail, but there has not been the same commitment to bus travel. The challenge that we have is there are pockets of good practice, but they are not joined up. The resources are not being pooled; there is no overarching vision; and there is no sense that disabled people have a right to live in and have access to their own homes, to have the personal support they need to be able live there, to

use mainstream transport and to use facilities in the community. I am here today to make that case.

Q26 The Chairman: I note that the written evidence from the Welsh Assembly Government, now called the Welsh Government, was from Carl Sargeant, the Minister for Local Government. On the basis of what we have been hearing, I assume that when we invite Ministers to appear before us they will include a Welsh Minister. But I am not at all certain that it would be Mr Carl Sargeant; it may well be Jane Hutt, who has as part of her portfolio equalities issues.

Paul Swann: Jane Hutt is the Minister for Finance. I doubt that she would come herself.

Q27 The Chairman: But someone has a particular brief on equalities. She has in the past held that brief.

Rhian Davies: Before the election, Carl Sargeant had the equalities brief.

Q28 The Chairman: We will write to the Welsh Government immediately following these questions.

Pam Duncan: On that point, one of the things that I missed was also a joined-up approach. It is absolutely essential and Rhian picked up on that. One example that we have is of a woman who had approached her social worker for a wheelchair and a ramp so that she could get out of her house. That social worker was unable to access the budget that would have paid for a wheelchair or the housing budget that would have paid for a ramp. Instead, the woman received 35 hours of community care a week. To some people, that would be essential, but, for that woman, it was neither what she needed nor what she wanted. The result was a longer-standing commitment to 35 hours of community care every week, but still no ramp or wheelchair. So she could not get out of the house. That shows that a joined-up approach is essential not just for independent living – what use is an accessible bus if you cannot get out of your house to get to it? – but also at corporate level in terms of decision-making, access to budgets and sharing resources. Leadership is crucial there. We have seen in Scotland that where you get leadership at corporate level, you really can effect change further down the line which people can feel.

Q29 The Chairman: On general issues, could I ask both Wales and Scotland – if I can describe you in that way – about the impact of the Government's proposals for reform of the benefits system together with cuts to local authority funding. Is it your view that this could lead to a breach of the Article 19 of the UN convention?

Pam Duncan: Absolutely.

Q30 The Chairman: In which way?

Pam Duncan: In several ways. As was alluded to earlier on, our view is that disabled people are the hardest hit as a result of a lot of the changes that have taken place. Disabled people face a double whammy from those cuts. For example, we are facing it in our pockets, but we are also facing it in our services. With only 49 per cent of disabled people in work, and almost 90 per cent of them in the public sector, we do not need to be geniuses to work out that their jobs are under threat. People on benefits are no better off because they will be disproportionately affected by the £18 billion of cuts. At the same time, charges for services are increasing. For example, in some local authorities in Scotland, the charge for community care has gone from 25 per cent of your disposable income to 50 per cent of your disposable income. In others, it is as high as 100 per cent of your disposable income. It is leaving disabled people very cash-strapped. The answer is not in them. Local

authorities are strapped for cash, and disabled people are too as a result of some of these changes.

On services, we are already hearing of disabled people being told by local authorities that they do not have enough money to support them to live in their own home so, as a result, they will provide them with an incontinence pad that will last for 12 hours so they will only need to see them twice in 24 hours. Where are the human rights and dignity in that? With cuts to DLA, services and disabled people's organisations—and we have a plethora of evidence of this that we can share with the Committee later in the interests of time—the cumulative impact will be that disabled people will not enjoy their right to family life and community living, as Article 19 states. The Independent Living Fund has a crucial effect on those people who draw down from it, specifically when local authorities are cutting back to such low levels.

Rhian Davies: I support everything that has been said. We have a particular concern in Wales because we have one of the highest proportions of disabled people in the population in the UK. We also have one of the highest numbers of people on incapacity benefit or employment and support allowance, as well as a very high number of people on disability living allowance, so the cuts will have a devastating effect, not only on individuals but also on communities because, rightly or wrongly, within Wales there are communities in which the benefit economy supports the whole community. We are not only seeing services being stripped away but access to things such as shops and amenities because there will not be the wherewithal for people to use those facilities. I particularly want to mention a case well known to us about the Independent Living Fund.

Paul Swann: A young man in North Wales, who is now in his late 20s, went to university and completed his degree. He is a wheelchair user. The local social services department knew that when his time at university came to an end there would be a range of issues, particularly around housing. While at university, this young man experienced independent living. He describes himself as fiercely independent. The situation that he was forced into arose particularly because of the closing of the ILF to new applications. He was one of the first to be affected by this. The consequence is that that young man is still living at home with his mother and father at the age of 27 or 28. He lacks independence. He is fighting for his independence. The financial aspect is critical to him. He does not want to live in shared accommodation with other people whom he does not know. He wants to live independently in his own home and to have an independent life. At the moment, because of the way that things are going, that is little more than a dream.

Q31 Baroness Campbell of Surbiton: We have covered this quite a lot but I am really going to get to the bottom of it. I want to know why, from what you have said and from all the evidence we have received so far, there is complete opposition to the closure of the Independent Living Fund and why those who have previously received ILF grants cannot look to their local authority for that support. We have been told that local authorities will do exactly what the Independent Living Fund did. It does not make sense to have a separate Independent Living Fund when disabled people can get direct payments from their local authority in exactly the same way. So where is this opposition coming from? Do you not trust your local authority to do this? I want to get to the bottom of why that is.

Rhian Davies: In Wales, we have over 3,000 people on the Independent Living Fund. I know that local authorities in Wales have taken full opportunity of the availability of the Independent Living Fund to apply for top-up funding for people, particularly those with high support needs, so we have accessed that fund. I think that £9 million comes to Wales through the ILF. Because that fund existed, that was the route that you took. Now that it has been taken away and the money is not being distributed, so far as I know it is not coming

back to us. We have floated the suggestion that the £9 million for people in Wales could come to Wales as a pot of funding, but we have not really progressed that. I know that it was controversial setting up the ILF. People could access it—

Q32 The Chairman: I do apologise. There is a Division in the Commons and we have to follow procedure and leave. I shall certainly be coming back, as will Mr Crockart, although I am not at all certain about my colleagues here. Mr Crockart and I will run down and run back—with difficulty.

The sitting was suspended for a Division in the Commons.

Q33 The Chairman: I apologise for that interruption. You were saying?

Pam Duncan: We were talking about the impact of the independent living fund. Baroness Campbell asked why we opposed its closure. We highlight several implications of it. We believe there are human rights implications of closing the fund. 17% of the independent living fund's budget was drawn down in Scotland which, as I am sure you are aware, is more than the Barnett formula that you might expect, so there will be a disproportionate impact in Scotland from closing the independent living fund, because our local authorities and disabled people were quite strong at drawing down on that. We are committed, through various international human rights instruments, to promote independent living for disabled people. I am sure that the Committee is acutely aware of those. We believe that with rising eligibility criteria, diminishing budgets at local authority level, taking this crucial millions of pounds out of the system for disabled people and their care and support will have serious implications for the realisation of these rights.

We also believe that those international obligations do not diminish in times of financial difficulty. In fact, they are even more important in order to protect disabled people who, it is widely documented, will take longer to come out of recession than anyone else. We think there are independent living implications, specifically. The independent living fund offered a flexible, portable alternative to traditional services and, of course, to the life and limb support that we have heard about that local authorities are offering at the minute. It was a crucial top-up to that.

Politically we think there are implications across local and national government, including devolved Governments. There are specific agendas to which the independent living fund was crucial, not least the self-directed support and personalisation agenda, but also the “whole-place approach” to public services. Sue indicated earlier that removing one card means that the whole house of cards falls. We all know that getting people back into work is very prominent in the political agenda. Without the independent living fund and that crucial top-up, for many disabled people work will be a distant reality. Further, there is the impact that removing that money will have on charging policies, but also for disabled people, some of whom are charged by ILF for their care and some are charged by local authorities. That has not been thought through and has some very significant impacts in Scotland.

Economically there will be less money to fund the care and support that is essential to meet the human rights of disabled people and to meet the aspirations of the independent living strategy and the vision for independent living in Scotland. Without all this together, disabled people will be unable to contribute to society in a way that could mean that they lifted themselves out of the poverty that they currently experience and play their part in lifting our society out of poverty and to be seen as contributors instead of consistently being seen as benefactors. That is why we are opposed to it.

On the question about local authorities, the bottom line is, trust them or not, they do not have the money. Even if the money was transferred, whether or not they would use it in that

specific way again comes down to decision-making. We would argue that, unless we have a strong commitment to collective co-production within such decision-making; and a strong commitment to disabled people's organisations and the right of disabled people to self-express, collective co-production is very difficult. If we are faced with questions in Scotland such as, "Are you happy with the freeze on council tax?". Most people will say yes, but if disabled people are not engaged in that debate, we get other things being squeezed. For example, in Scotland now we have a freeze on council tax costing the country £310 million, but at the same time they collected £350 million in community care charges in the same year. Collective co-production is essential for such decision-making, whether local authorities were to be trusted or not. The bottom line is that they do not have the money to fit the bill.¹ It is essentially moving one cost on to another department, or in this case another devolved authority.

Q34 Baroness Campbell of Surbiton: Thank you, I think you have answered that question now. Moving on to the Equality Act, neither Wales nor Scotland placed much emphasis in your written submissions on the role of the Equality Act 2010. What role does the Act play in the protection of the right to independent living? Maybe you can tell me why you did not place much emphasis on the Equality Act. You have both been big players in the Disability Discrimination Act.

Rhian Davies: First, I have to declare an interest. I am a member of the Wales Committee of the Equality and Human Rights Commission, and ex officio on its Disability Committee. We have an interesting situation in Wales. As I have gone on at length about, we have been trying to lobby the Welsh Assembly Government to introduce a national strategy on independent living. So far they have been resistant to that, but they have proposed that the Wales-specific duties in the Equality Act could be used as a lever to achieve our goals of independent living. We thought was an interesting approach. It is worth mentioning that the Wales-specific duties are very comprehensive and go significantly further compared to the public sector duties in England. We are looking at strategic equality schemes and strategic objectives, for example.

Having consulted with the Equality and Human Rights Commission in Wales, we agree that the Equality Act has an important role, particularly around the involvement of disabled people in terms of the planning and design of services, but on its own it probably would not be able to deliver the kind of overarching strategy on independent living that we are seeking. It will be an important tool, but in terms of an overarching strategy it is probably not the sole answer that we are looking for.

Pam Duncan: We take a similar view. It is very much a tool in the box for disabled people to use. You will be aware that the specific duties on the Equality Act are still under consultation in Scotland, so technically we do not have any specific duties yet in Scotland. We expect that that situation will change very quickly and we will have them. We welcome them as a tool to our box or a string to our bow. We fundamentally believe that things like assessing the equality impact of a decision are essential to mitigate against budgetary decisions that might have a negative impact on disabled people, but for that to be truly

¹ *Note by witness:* We believe without continuing the commitment of funds from the ILF, however that is delivered, with the cut backs local authorities and the wider public sector face within their own budgets, there will be no resource to pick up the funding which will stop in 2015. The inevitable consequence will be cuts in provision to those remaining on funding from the ILF at that time, alongside the accruing loss of quality of life among those who are presently being denied access to the fund.

effective, we think that disabled people have to be at the heart of decision-making. In Scotland, we also have the general duty to pay due regard, which we welcome, but we absolutely believe that we have to involve disabled people at the heart of decisions like this so that the impact can be fully understood. As our colleagues in Wales have said, it is very much a tool in the box. We see independent living as a human rights agenda. Underpinning that are various pieces of legislation that support disabled people.

Jim Elder Woodward: Overall, there has been a diminishing power in law to meet the rights of individuals. Taking away the resources of people to be represented undermines the impact of the equality agenda. Disabled people have no real recourse or legal support to take a case to court. That is a real infringement undermining individual human rights.

Paul Swann: As we know, the Equality Act 2010 is essentially about reducing, or ideally eliminating, discrimination against people with so-called protected characteristics. We are seeking something much stronger in terms of the need to dismantle the barriers to independent living for disabled people. That brings in the social model of disability, which in our case the Welsh Government signed up to in 2002. We are still a long way from having the social model of disability implemented in practice. The social model provides the foundation for independent living. As my colleagues have said, we will actively engage in developing the special duties in the Equality Act 2010, but we need much more than that; we need a national delivery strategy on independent living.

Q35 Mike Crockart: Turning to the broad topic of whether it is all about money, I am trying to look at other ways of doing things rather than just asking if there is enough money in the system. The evidence from Independent Living in Scotland to the Scottish inquiry on preventative spending said that independent living should be recognised as a preventative agenda. Could you spend a little time explaining what you mean by this and tell us of any policies that you think would promote prevention?

Jim Elder Woodward: We believe that every individual should be empowered to be active within the community, to be involved not only in employment, but in other areas of the civic and social life of the community. That person will be much more active and healthy than if they are sitting and waiting for someone to come in twice a day to help them cook and go to the toilet. There is a big divide between demand and supply of services. If you only cater for those with acute and substantial needs, that divide is going to get wider and wider. The two will never meet. But if you could spend a little more on preventive measures to help people live life, a life of quality and contribution, their health will be maintained, their psychological health will be maintained and they will not be such a burden on society later on in life, as they would be if you ignored them completely from the outset, because you concentrate all your resources on those presently presenting acute and substantial need.

The concentration on critical and substantial need is very short-sighted economics, because you are just getting a bigger and bigger backlog, going down the line. The other thing is that by providing preventative services early in a person's life, or impairment, you are going to increase the amount of tax people participating in the labour market can pay back to the exchequer, as well as more diversification of participation in the civic and social life of the community. All such civic, social and economic benefit to both society and family cannot be achieved if you spend only on those who are in critical need; and with such paltry provision given to meet immediate personal care only, in any case, they cannot contribute to their society and community. I hope that you could understand what I was saying.

Q36 Mike Crockart: Absolutely. Thank you. Turning to Disability Wales, you had a slightly different tack in your submission on this topic. In supporting the Welsh Government's sustainable social services commitments, you referred to the way that the

Welsh tradition of mutuality will be called on to inspire new co-operative models of care and support. Perhaps I could ask you to say a bit more about this and say what role mutuality could play in delivering independent living.

Paul Swann: In Wales we set off down the personalisation track in a similar way to In Control in England. But we have a very different situation in Wales, socially and economically. It became clear quite early on that we needed to develop a Welsh model of personalisation. An alliance of local authorities, providers, citizens and representative organisations have come together under the umbrella of the Wales Alliance for Citizen Directed Support. We are looking at how we can develop that Welsh model. As you say, we believe that the Welsh tradition of mutuality is a key factor in that. There are three core principles on which we believe that a Welsh model of personalisation should be based: choice and control; change and transformation; and, critically, community. We are very interested in developing that emphasis on community in Wales.

You mentioned doing things differently. Instead of the top-down approach that has been adopted in England, we are looking at how we can nurture local innovation so that different local authorities pick up and run with pilot projects that are appropriate to their circumstances. Critically, it is about citizen involvement. Disabled people know what we need to be put in place but very often decisions are made about us without us. That is not acceptable.

You mentioned the sustainable social services paper. It is very strong about getting things right from the start. If we can do that, we prevent problems and costs occurring further downstream. As colleagues mentioned earlier, there is evidence to show that independent living is cost-effective. We are quietly confident. We were quite pleased with the way that the sustainable social services paper took on board many of the recommendations of the independent commission on social services, which sat last year and took a lot of evidence. A lot depends on the National Social Services Partnership Forum, which will be Minister-led and set up shortly. If the mix of that is right, and if there are enough conversations and enough careful listening takes place, we hope we will be able to develop a community-based approach to personalisation, which will allay many of the genuine concerns that have been expressed in Wales.

Q37 Mike Crockart: I should like to come back with one very quick question. There seems to be a jarring happening there. You are talking about localism local authorities and community-based activity. Earlier we were talking about the difficulties of localism versus the general rights of disabled people. How do we marry the two up? If we want to promote mutuality and see whether that can work across a wider area of the UK and in Scotland, which I think it possibly would, there is a difficulty in that it will necessarily mean different care in different areas.

Rhian Davies: That is the dilemma. We would like to achieve a very strong commitment and direction from the Welsh Government that a right to independent living is essential and for them to lay out to local authorities and other public bodies what should be expected in terms of the kind of services that they deliver, but also what disabled people can expect in terms of rights and entitlements. Like Scotland, Wales has urban areas, post-industrial areas and rural communities. We also have Welsh-language communities. There is a natural diversity that we would want to celebrate and support, and not in any way do away with that. There is a sense in which, at local level, there will be initiatives that reflect that, but it has to be captured in an overall framework or in an overarching strategy that says, “This is our direction of travel; this is what we stake our place as a society on”. It is about the rights of individual people, who in this case are disabled people.

Pam Duncan: I relate back to what I said earlier about where localism supports the co-production of local communities and where it supports the right answer for the community. Like Wales, Scotland has very specific geographical or local issues that need to be considered. When that comes up against the human rights and independent living of disabled people, that is when it needs to be challenged. We would like a commitment to the universality of independent living and to see it as a universal right, regardless of where you stay. I live in Stirling just now. I would love to live in Glasgow. I work there and I travel every day, but I cannot move because the local authority's eligibility criteria are such that I may not secure the funding package of support that I already have. Their charging policy is so different that it might be unaffordable for me to move there. As a result, my carbon footprint is much bigger, because I am using the car every day to get to and from Glasgow and I am restricted in the number of hours and the way that I can do my work, all because I cannot get a care package in the local authority where I would like to be.

That sort of thing is an example of how those tensions across local areas come head to head with the human rights of disabled people. There needs to be a national framework of entitlements and rights that sees independent living as a universal right and sees human rights as the universal right that they are.

Jim Elder Woodward: There is a dilemma between localism and individual human rights. I cannot remember who said this, but somebody said that democracy is the best of the worst form of Government, because it always favours the utility of the majority. If you are a minority, democracy does not always help. The way out of this, I believe, is for the minority of disabled people to be encouraged through independent living to become part of the democratic process, so that their voice is heard among the other more major voices within democracy. Unless you can facilitate the social and civil as well as the economic involvement of disabled people, the voice of the disabled minority will not be heard. This is where localism needs to get involved with the needs of disabled people in the local decision-making process. I hope you can understand what I am saying. The present input of social care, concentrating as it does on basic personal care, will not allow you to participate economically and socially in the community. Until we have a voice in local democracy, localism will not represent our human rights.

The Chairman: Thank you very much for that. I think that you have summed up the essence of this very important evidence session. You have had a receptive audience here. Much of the evidence seems to run counter to the prevailing view of endorsing localism and devolution. As somebody who has supported devolution since the 1970s and continues to do so, I do not support it on the basis of devolving to be different, and certainly we do not support devolving to result in something worse.

When we come to have the Ministers before us, we will be asking questions about why devolution is resulting in something that is not necessarily better. I look forward to hearing their answers. No doubt they may be scribbling away already.

We will be writing to thank you and to pose other questions that we have been unable to ask today. Please feel free to add in the memorandum that you will be providing to us anything that you feel we have not covered today. It has been a very comprehensive session, but I am sure that there are other matters that you would wish to address. Thank you very much.

**Mike Smith, Monica McWilliams, Bob Collins and Duncan Wilson;
Diane Mulligan OBE, David Ruebain, Pauline Thompson OBE and
Karen Ashton**

Oral Evidence, 14 June 2011 Q 38–77

EVIDENCE SESSION NO. 2. HEARD IN PUBLIC

Members present:

Dr Hywel Francis (Chairman)
Rehman Chishti
Mike Crockart
Mr Dominic Raab
Mr Virendra Sharma
Baroness Campbell of Surbiton
Lord Lester of Herne Hill
Lord Morris of Handsworth
Baroness Stowell of Beeston

Examination of Witnesses

Mike Smith, [Commissioner and Chair, Disability Committee, Equality and Human Rights Commission] **Monica McWilliams**, [Chief Commissioner, Northern Ireland Human Rights Commission] **Bob Collins**, [Chief Commissioner, Equality Commission for Northern Ireland] and **Duncan Wilson**, [Head of Strategy and Legal, Scottish Human Rights Commission].

Q38 The Chairman: Good afternoon and welcome to this second session of the Joint Committee on Human Rights dealing with our inquiry on independent living. Could I give you all a very warm welcome and could you in turn please introduce yourselves for the record?

Mike Smith: My name is Mike Smith. I am a Commissioner at the Equality and Human Rights Commission, and I am also chair of its statutory Disability Committee.

Monica McWilliams: Monica McWilliams, I am the Chief Commissioner for Human Rights in Northern Ireland.

Bob Collins: I am Bob Collins, Chief Commissioner of the Equality Commission for Northern Ireland.

Duncan Wilson: Hello, I am Duncan Wilson, Head of Strategy and Legal at the Scottish Human Rights Commission.

Q39 The Chairman: Thank you very much, and thank you for coming such great distances to London to give evidence to us on what we consider to be a very important inquiry. I am sure you share that commitment. This first panel of course deals with the UN

convention and national implementation mechanism. I understand that you have come to an agreement that you will, I think in the words of our brief, agree to give joint answers to most questions, but that should not prevent you, if you feel you wish to demur or add something to the person who intends to speak on your behalf, from doing so. I will begin by asking a very straightforward question. Thank you for your submission. You all talk about the right to independent living in Article 19 of the convention as a combination of economic and social rights and the legal recognition of the right to equality for disabled people. Can you explain what the right to independent living in Article 19 of the convention means for disabled people, and what exactly it requires the UK to do?

Mike Smith: Yes, Duncan is going to answer that one.

Duncan Wilson: To interpret Article 19 of the convention, which of course is a new convention, I think we should have recourse in the first instance to the general rules of treaty interpretation, which the Committee will know are found in the Vienna Convention on the Law of Treaties. In essence these require interpretation in good faith according to the ordinary meaning, bearing in mind the context and the object and purpose of the treaty as a whole. Applying those principles to Article 19, that article should be understood at least in the context of Article 1 of the convention, which is the purpose; of Article 3, which establishes the general principles of dignity, autonomy, participation and so on and which can be understood as an indication of the object and purpose of the treaty; and of Article 4, which of course includes the general obligations under the convention.

With regard to the specific requirements of Article 19, it is useful to bear in mind the finding of a major study that was conducted under the auspices of the European Commission and published just last year, which applied those rules and found in general terms, as the Committee will be aware, that Article 19 recognises the right of disabled people to live independently and to be included in the community. It is closely linked with Article 12, which in essence restores the power—the legal capacity—to disabled people to make decisions, but Article 19 builds on that to provide that disabled people have the right to choose how to live their lives, to be fully included and to participate in society. It focuses in particular on the choice of where and with whom to live and being able to live in a community in a manner that supports and fosters inclusion and participation. That in turn requires that there should be access to support services and that general services should be equally available and accessible for disabled people.

In practice, as the Committee has no doubt noted, there are different interpretations applied across the United Kingdom to independent living. While this is not of itself necessarily a concern, the members of the independent mechanism have some concern that not all of those are rooted in the convention and draw directly on a human rights-based approach.

Turning briefly to state obligations that flow from Article 19, as I already mentioned, we should have reference to the general obligations in Article 4, which apply equally to Article 19—the review of existing laws, policies and practices, and the establishment of or measures to adopt new laws, policies and practices and so on in a comprehensive list, which includes among other things impact assessment. I hope we have the chance to return to that. All of those apply to the right to independent living, and I will not run through them all.

Some detail in terms of what is required with Article 19 was drawn out in the European Commission's supporting study that I referred to. That has specified that the obligations under Article 19 should include, among other things, taking effective measures to make a variety of living arrangements available to disabled people. If you look to the reporting guidelines, which the UN committee developed, this should include a range of options for residential, shared sheltered accommodation, and for providing the same choices as are available to others. There are obligations for undertaking a screening exercise to determine the most appropriate measures to remove the barriers that disabled people face in realising

the right to independent living, undertaking housing audits, involving disabled people in a process to assess difficulties in being included in community life and finally assessing whether disabled people are in practice compelled or obliged to live in any particular form of living arrangements. That includes assessing the availability of the support services, access to in-home support and safeguards against isolation. I want to check whether any of my colleagues have anything to add. No, thank you.

Q40 The Chairman: Following up on that, can you explain more fully how this particular right relates to the ability of the UK Government and the devolved Governments to take economic decisions which may engage many different rights of both disabled and non-disabled people?

Duncan Wilson: I will start to answer that question and see if anyone has anything to add. The whole of Article 19 should be read through the lens of Article 4. Some of the elements of Article 19—the obligations that I just enumerated—would be considered immediate obligations, and others would be considered akin to economic social and cultural rights and as such would include both immediate and progressively realisable obligations.

In terms of the steps that the UK ought to be taking to fully realise or achieve progressively the full realisation of the economic, social and cultural rights aspects, the state ought to be devoting what is called the maximum available resources towards the full realisation of those rights. In the current context it may be that those resources have to some extent diminished, whether in reality or according to policy. First, the actual availability of resources ought to be scrutinised and, secondly, the allocation of those resources should be subject to some scrutiny as well to ensure that adequate priority is devoted to those in the most marginalised or vulnerable situations, that non-discrimination is complied with and that the measures that the state has put in place in distributing those resources are reasonable and proportionate.

Q41 Baroness Stowell of Beeston: Are you satisfied that there is a uniform understanding across the UK Government, the devolved Governments and local authorities that disabled people have a right to independent living and of what that right entails? To put it another way, in your view are there any gaps in current law, policy or practice in the UK which are clearly in violation of the right to independent living protected by Article 19?

Mike Smith: I will start on that one and then we will see if any of my colleagues want to join in. On one level we are not quite sure that each of the devolved Governments has necessarily realised that there is a right of independent living. Moving on to your more general question about whether there are any specific violations, we think it is difficult at this stage to pinpoint anything that amounts to a specific violation, but we feel that across the UK there perhaps are a number of areas of policy or practice which either appear inconsistent with Article 19 or do not appear to contribute to its realisation. Duncan can tell you about the presumption that there was an intent from the drafters to promote de-institutionalisation and you will be aware of the BBC Panorama programme on the Winterbourne View case, which showed that in some situations there can be very inhumane, cruel and degrading treatment.

We think that human rights are placed at risk in closed communities where disabled people are segregated from the wider community. There are quite a significant number of such institutions in the UK. While we do not necessarily anticipate that that kind of treatment is prevalent, the continued existence of them as a mode of living arrangements for disabled people seems at odds with the aspirations of Article 19.

The second area we might focus on would be highlighting the requirement that disabled people should not be obliged to live in a particular living arrangement. At one end there is

the very serious issue that deprivation of liberty be safeguarded. This has been highlighted in the recent case the commission brought involving Steven Neary, which has shown that actions by the local authority have affected his rights under the European Convention Articles 5 and 8. The issue there is basically people not being given the right choice to have a right to family life. That has been a case in the last week.

Duncan was also referring to the question of whether there may be coercion to accept an obligation. It is true that no individual disabled person would ever be forced to live in a particular residential care situation, but if the resources are not there it may well be the reality that some local authorities will apply what is called the usual cost review procedure, whereby if the costs are too great they will say that they will not provide care in the home and they will only provide it in a residential situation. Arguably that person has no choice but to accept it because if they did not accept that level of care they would probably starve or die.

Disabled people do not currently have the legal right to transfer their assessment of care and support from one local authority to another. That clearly does impede people's choice of where and with whom they live because there is no guarantee that they would get equal provision of service between one local authority and the next. So we think there are many things that indicate that people's rights are not fully realised, or people do not have the same right, which is probably reflected by the increasing number of cases that have been brought under the previous disability equality duty and now the equality duty. We know, for example, that increasing numbers of local authorities in England and Wales are cutting their eligibility criteria to only critical or substantial, with some to only critical now. That clearly has a serious impact for whether or not the article can be fully realised by different individuals.

Q42 Baroness Stowell of Beeston: Can I just ask a supplementary to that? Have you or any of the other organisations commissioned any legal advice on the cases that you have referred to that you might be willing to make public or share with us?

Mike Smith: I would be very happy to review that afterwards and get some information back to you.

Monica McWilliams: We would be happy to do that, too. We have intervened in a number of cases and we would be happy to show you the legal advice.

Q43 Baroness Campbell of Surbiton: In our last evidence session, somebody said that they were very worried that they thought the language of rights in the narrative was disappearing from policy and practice. Is that your feeling or experience at all?

Monica McWilliams: When you ask someone from Northern Ireland about human rights, there is a long legacy in relation to the meaning of human rights and equality. Clearly in Northern Ireland I have had some difficulties in getting comprehensive attention beyond political and civil rights to the area of economic, social and cultural rights, which clearly this convention also covers. That is a very interesting point that you are making. On the enforcement mechanism, one of the points that we would make is that really in order to look at Article 19 you need to look at the Human Rights Act. We have used Article 8 in particular to intervene there and to give some meaning to the notion and the enforcement of independent living.

In relation to the policy-makers, it would remain the case that my commission would have enormous difficulty getting our policy-makers, particularly in the Office of the First Minister and Deputy First Minister, to take on making rights real, as we would say. We have had to remind them of their duty to do that under this convention in the reports that they make in terms of both the UN and the ODI. That is a concern, and Duncan, Bob, Mike and I have

spoken about the need to have an integrated approach to this. There is a much greater understanding of the need to have equality impact assessments than there is to have rights impact assessments. In the absence of that, your question is very pertinent.

Mike Smith: If I might add to that, the four of us have jointly written to Maria Miller in the last week expressing our concern that the current draft report on the UN convention issued by the ODI is perhaps failing in a number of areas. One of our disappointments is the lack of reference to human rights in that document.

Q44 Lord Lester of Herne Hill: I have an interest because I had the privilege of advising Monica McWilliams's commission about its draft Bill of Rights some time ago. I would like to ask two questions. First, regarding what Duncan Wilson was saying, our Committee will be trying to measure the extent of the real gaps, as far as we can, in a real, practical, hard-law and soft-law sense. One of the things that you did not say, but I hope you would agree with, is that our courts will seek to give effect to the object and purpose of the convention when interpreting legislation in order to ensure that there are no gaps. I hope you would agree with that, because it would seem to be an important way of filling what some of you have said are gaps, as a matter of interpretation. That is my first question.

Duncan Wilson: I completely agree with that. The approach of the superior courts in the UK has been consistently to look to interpret to the extent that that is possible—as the Committee is well aware—domestic legislation in the light of international obligations. Interestingly, the Strasbourg court—the European Court of Human Rights—has begun to take note of the convention in interpreting the European Convention of Human Rights in at least two cases that I am aware of, one involving Switzerland and the other involving Slovakia, I believe. As such, the Human Rights Act, for example, can be used as a lens at least through which to interpret the rights that it includes in the context of the more detailed provisions of the convention as they apply to disabled people.

Mike Smith: There is also the way in which the courts have been happy to apply the Human Rights Act when determining whether cost-based decisions are fair or not. One of the cases EHRC is currently supporting is that of McDonald v Kensington and Chelsea, which, as you will be aware, is going through to the Supreme Court. Sometimes in that situation judges seem a little reticent to use the HRA when there is a question around the application of resources, and whether or not that was fair or appropriate. We would also be happy to provide further information to the extent that it is appropriate.

Bob Collins: To make the response to Lord Lester's question more comprehensive, a couple of months ago the High Court in Northern Ireland invoked the convention and the rights of persons with disabilities in the PF and JF case, precisely so as to underline the importance of the gap that was identified in the domestic law of Northern Ireland. Even though the convention was not an issue in the case, I think that it made a very helpful and enlightened judgment in terms of identifying ways in which a resolution could be found above and beyond the call of duty, which is a clear indication of what you have identified.

Monica McWilliams: The judicial review judge found in that case that there was a disparity in relation to the direct payment for carers between Northern Ireland and England. We intervened as a third party in the court, drawing attention to the convention rights and we are now allowed to follow up the judgment with the trust, asking the trust to what extent it is taking on board the rights in the convention in order to apply the judgment.

Lord Lester of Herne Hill: Thank you. Could I ask my second question?

The Chairman: I thought that you had asked two questions.

Lord Lester of Herne Hill: No, only one so far.

The Chairman: This is a very brief supplementary then.

Lord Lester of Herne Hill: I will ask it later.

The Chairman: Okay, thank you. Lord Morris.

Q45 Lord Morris of Handsworth: You have all highlighted the role that equality legislation, particularly the Equality Act of 2010, will play in securing the rights to independent living. But you have all stressed that this protection is only part of the legal policy framework that secures the right to independent living in the UK. Can you briefly explain how these various forms of protection work together, and whether there are relevant gaps in the protection that exists? Can you also say what, if anything, Article 19 of the UN convention will add to domestic law?

Monica McWilliams: This is a question in relation to Equality 2010, which I think is more relevant to somebody from EHRC, because, as you know, that legislation did not extend to Northern Ireland. Then we can pick up our particular difficulties in relation to our more home-grown legislation that still applies.

Mike Smith: I will pick that up then. First of all, there is no overarching domestic or legal protection in relation to Article 19—no direct right to independent living—as set out in our written evidence. But we believe there is some potential for those rights to be included in the interpretation of the Human Rights Act, particularly Article 8. The relevance of Article 8 to the right of independent living was demonstrated in the judgment handed down by the Court of Protection concerning Steven Neary, which I mentioned earlier. Hillingdon Council was judged to have unlawfully deprived Steven, who has autism, of his liberty and of failing to respect his rights to private and family life by detaining him in the support unit. That was quite an important case that raised this point.

Each of the UK's national human rights institutes promotes and protects the full range of civil and political as well as ESC rights. These rights, which are instrumental to the realisation of Article 19, were not incorporated into domestic law. The point we are noting is that there are considerable variations in, for example, the law regarding community care across the UK. They may significantly influence the realisation of Article 19. We have quite a lot of detail that we are happy to provide later, but there are issues such as policies on whether charges are being made for social care, the existence of national eligibility criteria, which are being proposed in Wales but not in England, the variation of application of those criteria across local authorities and some of the underlying principles in community care law between the devolved Administrations. So there is variation in terms of the legal issues and the extent to which Article 19 can be realised through the range of laws that we have.

Q46 Lord Lester of Herne Hill: We have agreed so far that the courts in their interpretative role, while recognising the separation of powers with the political branches, will interpret our legislation where they can compatibly with this convention among others. You say that there has been no direct incorporation of the right to independent living. Would you agree that, although the equality and human rights legislation differs between us here and Northern Ireland, it will be interpreted and given effect in a way that accords with the convention where it is the proper role for the courts to do so rather than the political branches?

Duncan Wilson: While I would agree with that, I think the point Mike was making was that it depends on the interpretation that one puts on the final part of your question. If it is one that excludes the possibility of courts determining whether measures to progressively realise economic, social and cultural rights are not properly within the domain of the courts, then I would disagree with that. That is the aspect of Article 19 that is not currently incorporated

into domestic law so that our courts cannot, in the way that the Constitutional Court of South Africa, has famously done so repeatedly, determine the reasonableness of steps that the state is taking to realise the ESC rights dimensions of Article 19. The flipside of that, of course, would be whether any steps further away from the full realisation of that right are reasonable and proportionate, and the strong presumption against retrogressive measures, which of course is consecrated in international human rights law.

Q47 Mr Sharma: In the submission you highlight that the Equality Act 2010 does not apply in Northern Ireland, where the DDA continues to have effect. However, you also told us that the 2010 Act does not go far enough. Can you explain further how you think the application of the DDA as opposed to the 2010 Act will impact on the right to independent living for disabled people in Northern Ireland?

Bob Collins: This is uniquely an issue for Northern Ireland since the enactment of the Equality Act 2010. The reality is, as a consequence, the people in Northern Ireland, across the entire range of disability legislation, are disadvantaged relative to those who live in other parts of the United Kingdom. There are a number of points that could be made specifically in relation to disability. The first is the more general point: the fact that the legal framework that is in force is the 1995 legislation provides a context for public policy formulation that offers a quite different context from that which obtains in Great Britain. That is not without its significance, and touches upon aspects of the point Lord Lester made a moment ago.

The second issue is that there are protections available to citizens in Great Britain now that are not available in Northern Ireland. On the face of it, it seems to be quite at variance with the richness that can be implicit in the notion of separate jurisdictions within the United Kingdom if one of the consequences is that people who live in one of the jurisdictions will be significantly disadvantaged because of the fact that the legislation has failed to keep pace. Without going into considerable detail in relation to the differentials between the two—and we can provide information to the Committee separately on that—I think that there are a number of issues that are worth mentioning.

The first is that the House of Lords decision in the Malcolm case had significant impact on disabled people and the extent to which the protections envisaged in the legislation became no longer available to them. That has now been resolved in Great Britain but continues to be the case in Northern Ireland, where it represents a serious inhibition on the life and potential of people with disabilities.

The second area where the Equality Commission had long advocated change was in removing the specific list of capacities in the DDA, which could serve to delimit the area of application of protection under the Disability Discrimination Act. That still obtains in Northern Ireland but does not in Great Britain. The absence of sensible harmonisation across the various measures and within the measure is an issue still to be addressed in Northern Ireland.

All these issues, it seems to us, represent difficulties in terms of frustrating the intentions of the convention and the capacity to fully realise the objectives of the convention. Even if the devolved Administration were enthusiastic about the independent living provisions, they would simply be incapable of being represented in the day-to-day reliefs available to people. Even if it is the case that the courts may interpret individual circumstances in the light and against the background of the convention's provisions, recommendations and requirements, the reality is that, for most individuals who are either going about their lives or who are engaging with public bodies or with Government, the position remains as it was. There is a disadvantage laden on an area that is already laden with difficulties in any event. So this is a serious issue, which is also reflected in a very good paper on disability that was brought forward by the Promoting Social Inclusion Working Group 18 months ago—it still has to be

vouchsafed a response from the Office of the First Minister and Deputy First Minister. I am not saying that that would not have happened had the legislation been changed, but I think that the context within which those kinds of decisions were taken would be more easily amended.

The final point on this is that not only is there a difference between the Equality Act 2010 in Great Britain and the DDA in Northern Ireland, but the statutory duty in respect of disability in Great Britain is distinctly different from that which now obtains in Northern Ireland, to Northern Ireland's disadvantage.

Monica McWilliams: It is good that we have this opportunity in front of the Joint Committee because, as I have said before, we are never able to make this point in Northern Ireland, where there is no committee such as this. It is only here that we can make the point about disparity between the devolved regions.

Q48 Mr Sharma: To follow up on that, what do you think the limitations of the 2010 Act are and how will these impact on the right to independent living?

Bob Collins: Let me just identify two issues that we have made the focus of attention over the years. The first is in relation to the preference for the social rather than the medical model of disability. The social model is reflected in the convention but not in the Equality Act 2010, and less still in Northern Ireland. We believe that to be a limiting factor that makes it much more difficult to fully incorporate the intentions of the convention.

The second area to which I have drawn attention is that, within the definition of disability, the emphasis is on disability of a long-term character, which overlooks the real issues and concerns of people who may have short-term but intense disability for which there is no formal protection under the current definition. For some people that is an issue of real substance and in the judgment of the Equality Commission for Northern Ireland it should be amended. There were other areas of exemptions in the legislation that still obtain, which in part gave rise to reservations in relation to the convention being registered by the United Kingdom. The first two, in terms of the model that underpins the legislation and the persistence with the inclusion of "long-term" in the definition, represent weaknesses in the legislation that in our view could act to make the full realisation of the potential of the convention more difficult.

Mike Smith: The EHRC pursued that same point on long-term and short-term conditions when the Equality Act was going through, and in relation to those people who had fluctuating conditions that may not have been covered.

Chairman, may I make a request? Someone in the room has a mobile phone or a BlackBerry on and the data is interfering with the induction loop. Perhaps they could switch it off.

The Chairman: Can everybody double-check?

Mike Smith: Thank you.

Q49 Baroness Campbell of Surbiton: I am going to ask about the public sector duty. During our last evidence session, witnesses told us that they were concerned that the new public sector equality duty to involve could slip back from the old disability equality duty. Do you agree with this assessment? If so, what steps are you taking to ensure that the general equality duty and any specific duties provide effective tools to support equality and independent living for disabled people?

Mike Smith: Perhaps I might start at the end of that question and move back. We are in the middle of finalising our recommendations and guidance on the equality duties. As you will be aware, the English-specific duties are yet to be finalised, so the guidance in that area is still being worked on. Going back to the substance of your question, we think the general duty in the Equality Act remains broadly equivalent to the previous disability equality duty.

In reference to Article 19, it is relevant particularly in promoting disabled people's participation in public and community life. You will be aware that the duty is supported by the secondary legislation, and that this is devolved in the cases of the Scottish and Welsh Governments. This means that there will be three distinct approaches to the so-called specific duties across Great Britain in addition to the maintenance of the previous equality duty in Northern Ireland.

This might present significant challenges for various bodies that work across the country, including the EHRC itself, because we are subject to the equality duty and need to work across all three nations, and those differences will provide some potential challenges. The GEO has recently consulted on the specific duties for England, and we are yet to be advised of its final conclusions on the matter, but in the EHRC's response we highlighted the fact that the duty to involve was an issue of particular importance to the role of the Equality Act in implementing the UNCRPD. The disability equality duty was quite unambiguous in its requirement of public authorities to involve disabled people in meeting the duty. It is unclear from the Government consultation whether we really can anticipate a similar level of clarity in the new duties, but we really hope that we will get that. We think it is incredibly important. Scotland has yet to publish its proposed specific duties. However, Wales published its specific duties on 29 March, which include clear requirements to involve disabled people in setting the objectives and impact assessments and in developing a strategic equality plan. So we do have some concerns and reservations, but we await the remaining detail from the Government.

Q50 Mike Crockart: I refer back to a previous session we had where disabled people's organisations told us that they were particularly worried about the inclusion of the Equality Act 2010 in the Cabinet Office red tape challenge. None of your submissions mentioned that particular aspect in your evidence. Why was that? What do you think about that exercise? In particular, have any of you been consulted by the Cabinet Office in relation to the exercise?

Mike Smith: I am starting on this one as well. Our starting point is that we have no desire for bureaucracy to stand in the way of achieving improved equality outcomes and human rights. The convention itself makes frequent reference to measures that are either appropriate or effective in order to realise rights, so there is a real emphasis on doing things well. If there are more effective and appropriate means of realising the rights of disabled people, then they should be implemented, and that should be something that is welcomed. We understood the red tape challenge in the first place to be about regulation, not primary legislation, so we were a little surprised to find the Equality Act to be considered by that review in its entirety, which we consider somewhat anomalous. The Act was passed by Parliament a little over a year ago and key elements have yet to be implemented. We would have thought it perhaps a little premature to review its impact already. We are quite heartened by the majority of the responses that have been included on the red tape challenge, which are significantly positive towards the Act and towards its aims and objectives. At least we know that the majority of people out there are on our side.

Monica McWilliams: The answer to the other part of your question—whether we have been consulted—is no.

Bob Collins: And no.

Mike Smith: I understand that commission officers have been participating behind the scenes for the GEO, but I would not say that we were formally consulted.

Q51 Rehman Chishti Outside the public sector equality duty, can and should the UK Government, devolved Governments or local authorities assess the impact of proposed policy changes on the right to independent living before they are implemented?

Mike Smith: I get a break; Duncan is taking this one.

Duncan Wilson: There are measures which we feel could and should be implemented just to that end. I would highlight four—impact assessment, indicators, monitoring and action plans—but in the interest of time I will focus on impact assessment. As the Committee will know, Article 4(1)(c) of the convention explicitly requires that the state take into account the impact on the rights of disabled people of all policy and programme decisions. In order to ensure that that happens, the development and use of human rights impact assessments alongside equality impact assessments is something that a number of the commissions are pursuing in our jurisdictions. In our case in Scotland, the Scottish Human Rights Commission has commissioned a review of international and domestic practice on the use of human rights impact assessment, which recommended that in the UK context human rights impact assessments should always be aligned with equality impact assessments, and set out an eight-stage process that would ensure that a human rights approach was taken both to the process and to the outcomes of impact assessment.

The approach which we have taken based on that study was welcomed by the Scottish Government, who are developing an integrated approach to impact assessment and local authorities, through the Convention of Scottish Local Authorities and other key partners including National Health Service Scotland and the Scottish Government Health Directorate with whom we worked with them throughout last year to develop an integrated impact assessment process, which was piloted in eight policy areas with some success.

The key benefit of integrating human rights in addition to equality impact assessment is that it allows consideration not only of differential impacts of a policy or programme on different people based on their identity or status, but also an assessment of any disproportionate or degrading impacts on an individual based simply on their common humanity. On one hand, it allows an assessment of whether any policy or programme would risk a level of treatment which fell below the red lines in human rights and interfered with or impeded the realisation of absolute rights, and on the other hand it ensures that any impacts on qualified rights are proportionate from the alternative choices that are available, the one that is least restrictive of the rights of the individual is chosen.

The process of impact assessment is also important. A participatory process helps to ensure that the cumulative impacts of a range of different policies and programmes rather than their discrete impacts can be understood through the lived experiences of individuals. Gathering evidence and analysing the outcomes of that consultation or participation process through the rights analysis would avoid any negative impacts on absolute rights and would allow a process of mitigation for any impacts on qualified rights to ensure that they are the least restrictive. I would link back to the answer to a previous question asked by Lord Lester. So far as the decision would impact on the realisation of economic, social and cultural rights, it would allow a structured process by which public authorities could consider whether any retrogression, retreat or reduction in the realisation of those rights was reasonable with regard to the full range of human rights and the allocation of the state's resources to realise those.

In conclusion on the benefits of integrated impact assessment, as well as reducing the risk of a successful judicial challenge in the way that Lord Bingham indicated in the *Shabina Begum* case, the integrated impact assessment of human rights and equality impact assessments would help public authorities to make the right decision the first time and would improve the quality ultimately of public service delivery to make it more person-centred by putting

the individual human being at the centre of public decisions. It would enable them not only to ensure or be more confident of compliance, but to move towards best practice.

Q52 Baroness Campbell of Surbiton: In a recent decision against Birmingham City Council, the Administrative Court quashed a decision to limit access to funding for social care for non-compliance with the disability equality duty. I have a few questions that flow from that. Do you think the same decision would be taken under the new public sector equality duty? Birmingham said that there was no money in its budget and that cuts will need to be made. Can you explain how you think a local authority should properly approach its decision-making responsibilities in order to comply with the public sector equality duty and support the rights of independent living? What steps are each of you taking to ensure that the rights of disabled people are considered by central Government, devolved Government and local authorities in their decisions on money savings?

Mike Smith: The Birmingham case is very interesting and to an extent it echoes the Hammersmith and Fulham case a few years ago. There are some interesting things to consider. We know that local authorities have got finite resources and need to work out how to deploy those across their statutory, social and other responsibilities and objectives. If the different impact on different groups has been properly considered in an open and transparent way it is more likely that the impact of the various options and perhaps any unintended consequences or disproportionality will also have been considered, and decisions would be made in a more transparent way. That would hopefully give greater transparency and accountability in respect of local citizens, which would obviously be to the advantage of promoting the localism agenda, because decisions are seen to be made with full understanding of their impact.

I hope it would not be different under the public sector equality duty, because if the general duty of the new duty is broadly the same, hopefully local authorities would come to the same conclusion as I have just talked about. That will depend to an extent on what the final details of the specific duties are, particularly for England, and whether it indicates any particular processes. We hope that there will not be process for process's sake and that those extra guidelines will give some level of good clarity on the sort of things authorities need to consider when making those decisions.

In terms of what we are doing at the commission, we are currently in the middle of a Section 31 assessment on the Treasury and its spending assessment in the Comprehensive Spending Review. We want to ensure that it has adequately considered equality impact decisions while doing the Comprehensive Spending Review, particularly their cumulative impact. That will be reporting later this year; we will be sharing the results with the Treasury and then making them public. We also wrote to all local authorities this January asking how they have had paid due regard to the previous equality duties when making their final decisions. We will be doing that over three key areas: transport services for disabled people; violence against women and girls; and organisations that provide information and advice to ethnic minority groups. We are currently collating those responses and will be reporting on that.

Last October, the commission launched new guidance to help decision-makers to put fairness and transparency at the heart of these difficult financial decisions, and the guidance sets out what is expected of them and others to comply with the public sector Equality Duties by ensuring that the processes that they follow to assess the impact of equality on those financial proposals are robust and that the impact that the financial proposals could have on protected groups is properly considered. So we have been doing a fair amount. Bob, you may care to pick up on Northern Ireland.

Bob Collins: I would like to make a few relatively brief points to complete that answer. First of all, the convention contains provisions for the close consultation and involvement of disabled people and their representative organisations in decision-making and policy formulation and in full participation in the conduct of public affairs. It was to facilitate that purpose that the disability duties were introduced in Northern Ireland under the DDA 1995. There are duties on all public authorities under Section 75 of the Northern Ireland Act to give due regard to the necessity of promoting equality of opportunity for a range of categories, including people with disabilities.

Within the Equality Commission we enjoy a much greater opportunity to have a structured engagement with public authorities in respect of their Section 75 duties than is available in relation to the disability duty because of the formal mechanism that they need to provide equality schemes, which we must approve, and because of our capacity to investigate complaints made in relation to any failure or perceived failure to honour those commitments. That discipline does not exist in relation to the disability duties, which is another of the abiding differences between Northern Ireland and Great Britain. Having said that, we clearly see the potential of both of those duties as areas within which we can situate the convention more clearly.

The second point that I wanted to make was that part of the work that the Northern Ireland Human Rights Commission and the Equality Commission, which jointly are the independent mechanism for Northern Ireland in respect of the convention, are doing is finding ways in which we can more effectively integrate the convention and the obligations under it within the duties that are placed on public authorities and within their responses to them. We are preparing a formal guidance on a joint basis. As the Equality Commission, using our statutory capacity, we will issue that to all public authorities to make clear how the provisions of the convention should be incorporated into the statutory duties that they have in respect of both the disability duty and the Section 75 duty, which includes promoting equality of opportunity in respect of disability.

The Chairman: I have to stop you at that point. We need to ask one final question. I am very conscious of the time. I do apologise to you. We will be writing to you with the questions we have been unable to ask, but I want to be fair to the next panel as well.

Lord Lester, you wish to ask a supplementary and then a substantive question.

Q53 Lord Lester of Herne Hill: It is important, and would help the Committee enormously, in my view, to distinguish between aspirational or political matters and matters of legal entitlement and rights. It would be very helpful if, after giving evidence today, one or all of you were able to produce a note—and Duncan Wilson came closest to following what I am trying to ask—seeking to distinguish between hard law, the kind of law that judges can and should interpret and apply, and soft law, which is largely aspirational and which the political branches of the Government should heed. If that can be done I personally would be very grateful.

You have all talked about the disparities between Northern Ireland and Britain, and the difference in legislation and so on. In terms of the machinery of Government, and forgive me if I get this wrong, I assume that the equality legislation is not devolved but is a matter that is addressed by the UK as a whole. Am I wrong about that?

Bob Collins: It is devolved.

Q54 Lord Lester of Herne Hill: So your complaints about the lack of consistency and uniformity under the devolution scheme are complaints really to the Northern Ireland devolved authorities.

Bob Collins: And are consistently and uniformly made to them.

Q55 Lord Lester of Herne Hill: So if we as a Committee were to be critical of the situation we would essentially be addressing that part of our Report to the Northern Ireland authorities rather than to Westminster and Whitehall. Is that right?

Bob Collins: Yes, it is entirely within the competence of the Executive and Assembly in Northern Ireland to amend the disability legislation in the way that it has been done in Great Britain.

Monica McWilliams: However, Lord Lester, your question raises an interesting constitution conundrum that both Bob as Chief Commissioner for the Equality Commission and I as the Chief Commissioner for Human Rights constantly have to deal with. I am not devolved—our Commission is not devolved. I rest here with Westminster and am responsible to Parliament, and therefore the UN convention and the state duties under it fall here. Therefore we respond, both in parallel reports and in shadow reports, to the ODI, but our devolved Administration has responsibility for seeing through those duties, which fall to the Office of the First Minister and the Deputy First Minister. Equality is devolved; human rights is not devolved.

Duncan Wilson: To further clarify or confuse the picture, in terms of Scotland equality remains a reserved matter, although elements of equal opportunities are devolved. In relation to the obligations of the state under the convention, while the international obligation remains with the UK, the Scotland Act clarifies that the responsibility for implementing international conventions lies with the Scottish Parliament and Scottish Ministers within their areas of competence.

Q56 Lord Lester of Herne Hill: Again, in order to avoid the wrath of the Chair in my asking too many questions, it would be helpful, to me at any rate, if all of you could produce a kind of map, taking some practical examples and showing how there is a denial of equal protection under the law because of the mess created by different jurisdictions, different Government machines, and so on, when we are dealing with a single duty to comply as the UK as a whole with the convention obligations. That would assist the Committee as a whole if that could be done, and you may have done it already in written evidence, in which case I apologise, but I would certainly like to see the wood for the trees.

The Chairman: Thank you Lord Lester. That is now one hour. I am most grateful to you all. I apologise to you as there are a number of written questions that we will be sending to you, but beyond that, as Lord Lester has quite rightly pointed out, there may well be other issues, including his, that you may wish to add as a consequence of this evidence session. I now ask the witnesses for the second panel to come forward please.

Examination of Witnesses

Diane Mulligan OBE, [UK Candidate for the UN Committee of Experts on the Rights of Persons with Disabilities] **David Ruebain**, [Solicitor, Former Director of Legal Policy, EHRC, Chief Executive of the Equality Challenge Unit] **Pauline Thompson OBE**, [Co-author, *Community Care and the Law* (4th Edition)] and **Karen Ashton**, [Solicitor, Public Law Solicitors].

Q57 The Chairman: Good afternoon and welcome. Could you all introduce yourselves please?

Diane Mulligan: My name is Diane Mulligan, and I have been nominated as the candidate to stand for the UN convention's expert committee elections in 2012. I am also a member of Equality 2025, which is a group of independent advisers to the UK Government.

Karen Ashton: My name is Karen Ashton. I am a solicitor from Public Law Solicitors in Birmingham, and I specialise in community care law.

David Ruebain: My name is David Ruebain. I am currently the chief executive of the Equality Challenge Unit, which is the higher education sector's equality and diversity resource. I was the director of legal policy at the Equality and Human Rights Commission until last year.

Pauline Thompson: I am Pauline Thompson. Until recently I was a policy adviser at Age Concern, and latterly Age UK. I am now a freelance trainer, and I am also co-author of *Community Care and the Law*.

Q58 The Chairman: Thank you. As you know, this panel is going to focus on protecting the right to independent living in the UK. This is a question addressed to all of you, but you do not all necessarily have to answer: please feel free to duck out of the question if you feel that another person has answered it for you. We obviously want to focus on the implementation of the right to independent living under the UN convention by the existing legal and policy framework. Are you all broadly satisfied that the current legal and policy framework in this country supports the right to independent living, and, if not, are there any crucial areas that you would suggest need amendment?

Karen Ashton: I am happy to kick off. I specialise in community care law. In my view, community care services are key to achieving the right to independent living, in that they are the right to state support services for people with disabilities. I am not satisfied that the approach to eligibility for those services is Article 19 compliant, if I can put it that way. Please forgive me if I am repeating material that the Committee is already aware of, but I wonder whether it might help to set out the basic framework for determining eligibility for community care services. Although there is a fundamental statutory duty to assess and decide whether such services are called for in relation to any individual who appears to be potentially in need of such services, the way local authorities should approach determining eligibility is set out in statutory guidance, and what that requires of an assessor is for there to be an assessment of the risks to independence and wellbeing if services are not provided to meet any particular specific presenting need—for example, a need for support to be able to get out and about into the community. The assessor must grade the risks into one of four bands: critical, substantial, moderate, and low. We can probably talk more later about the Birmingham case, where Birmingham decided to move to what was called a critical-only policy.

The guidance itself defines what risks count as critical, substantial, moderate and low, and I thought it might be helpful to set out the definitions in the statutory guidance of a substantial risk. A substantial risk arises if abuse or neglect will occur if: there is, without the provision of services, an inability to carry out the majority of personal care and domestic routines; involvement in many aspects of work, education, learning et cetera will not be sustained; the majority of social relationships will not be sustained; the majority of family and social roles will not be sustained; and there will be only partial choice and control over the immediate environment.

What the guidance permits is for each local authority to set its own eligibility threshold; most local authorities, until now, have had an eligibility policy whereby they will provide services to meet needs that give rise to substantial and critical-level risks. The guidance on its face would permit a local authority to move to a critical-only policy. The consequence of that is that those kinds of risks to independence that I have just described would not qualify for eligibility for support services. I question whether that can be compliant with Article 19—for example, the requirement that the state ensure that persons with disabilities have access to a range of in-home residential community support services, including personal assistance to prevent isolation or segregation from the community.

To take you back, a substantial level risk could be one where the majority of social relationships will not be sustained, but in a critical-only policy you would not be eligible for a community care service to ensure that that risk did not arise. In terms of the statutory guidance, I do not think that promotes independent living that is compatible with the vision of Article 19, and, if one treats Article 19 as an aspiration, rather than obviously conferring an immediate domestic right, nonetheless there is nothing in the statutory guidance which promotes a progressive realisation of that level of independence either. It is significant that statutory guidance post-dated the UK's ratification of the convention. I am sure there are other points that people want to make.

Q59 The Chairman: Could you be brief, because I am conscious that we have got lots of questions, and there is a danger that you might be anticipating some other questions.

Pauline Thompson: With my background for older people, where I am concerned that it is not working in practice is the routine age discrimination that we see. First, the amount of services that older people actually get still seems to be very much concentrated purely on the absolute basic personal care needs of getting out of bed and going to bed at night. Therefore, even if the local authority can tick the right boxes that they are giving direct payments, and can say, “Yes we are promoting independent living”, the direct payment will reflect that very small level of service. The other thing is to be aware that there are about 400,000 people in residential care, most of whom are older people, and Article 19 does talk about having access to residential services. We need to be very conscious, and it does often get overlooked, that when you are commissioning residential care you need to be looking at independent living aspects, and helping a person to have control and choice within that residential situation. I want to point out those two points at the moment.

Q60 Lord Lester of Herne Hill: This really follows from what Karen Ashton was saying before. Would you think that Article 19 imposes a target or aspirational duty that is designed to guide socio-economic policy rather than a directly enforceable legal duty with a relative legal right?

Karen Ashton: Certainly my view is that it does not confer a direct domestic right to independent living. There are a number of ways that it is relevant in a domestic setting—you mentioned one earlier about interpreting primary and secondary legislation—but it is also relevant to the public sector equality duty, for example, where there is a proportionality

exercise to be undertaken. It seems to me that not only convention rights under the Human Rights Act but also rights under the UN convention would be relevant in that context. It is very underused at the moment domestically; practitioners are not yet that familiar with it, but that will develop over time.

Q61 Lord Lester of Herne Hill: If a public authority just put it in the waste paper basket, even if it was only a target duty, would that not be a public law wrong?

Karen Ashton: Yes, I agree.

Pauline Thompson: One of the things that I find when I am training is, when I talk to social workers about the UN convention and Article 19, they have often never heard of it before, and sometimes come out with comments like, “In your dreams”. This is news to them. One of the things that I was concerned about is how little there is on the Department of Health website. As far as I could find, there is nothing about the UN convention that actually gives local authorities a bit of guidance.

Q62 The Chairman: Diane Mulligan, do you wish to respond to this?

Diane Mulligan: I will briefly. I would like to talk more in the round of what Article 19 is and how it also relates to other articles in the convention, if I may at some point. One of the obligations of the state having ratified this disability convention is to review its current legislation and policy, and see how that relates to independent living, and living with dignity in the community. The Government has so far not done that. What it has provided is a draft report to the UN on its reporting duties to the UN committee. For me that report really lacked the language of human rights within it; it did not adopt a rights-based approach, and in terms of Article 19 it did not fully address some of the gaps that need to be closed to ensure that disabled people in the UK can realise that right.

For me, there is a need for disabled people themselves to know what their rights are around independent living, and living as part of the community, so that they can demand those rights. However, the Government as the duty bearer also needs to be able to provide that, and currently I do not believe that to be the case.

Q63 Baroness Campbell of Surbiton: Do you think that the existing legal framework—whether that be the Equality Act 2010, the Human Rights Act 1998, or the general principles of judicial review—provides an adequate means for disabled people to challenge treatment that is incompatible with the right to independent living? For instance, EHRC told us that the HRA 1998 had played a limited role in protecting the rights of disabled people. Would you agree with that assessment? What are the key barriers? Are they substantive or are they practical?

David Ruebain: Let me kick off with some thoughts on that. Until recently the direction of travel, if I can characterise it in that way, was to afford disabled people strengthening rights to independent living, in the matrix of arrangements that arise. That would be through the public sector disability equality duty that you have heard about under the Disability Discrimination Act, through incremental use of the Human Rights Act and through the matrix of community care provision and welfare benefits support such as disability living allowance and also, I would say, through a slow but growing realisation among the judiciary of the meaning and importance of independent living for disabled people.

However, recently we have seen a number of proposals that give cause for concern in that regard and suggest that the progress that has been indicated, and is evidenced by some of the cases such as the Birmingham judgment, may be slowing or even stopping. For example, I point to the proposals to limit the scope of disability living allowance for disabled people, whether it be for disabled people in residential care homes or more widely, which may reduce their independence substantively—I have regard not only to Article 19 but to

Articles 26 and 30, the rights to habitation and to participation in social and cultural life. There are also the proposals to limit housing benefits and the practical steps that Karen and others have referred to where social services departments are, in fact, limiting the availability of resources to disabled people. The constellation of all of these developments, obviously in a political environment where there is fiscal retrenchment, means that disabled people are at the very hard edge of being affected by legislative and economic changes.

To answer the question, do I think that the legislative framework now is sufficient to ensure independent living? I would say no. We need more, whether that be further guidance on interpretation of community care legislation, or a strengthening of the law, for example, in public sector duties or otherwise.

Q64 Baroness Campbell of Surbiton: Do you think Article 19 will play a significant role in this?

David Ruebain: I hope it will. One of the things that we obviously have not seen yet is the actual operation of the optional protocol. As far as I am aware, we have not had any cases taken yet, and I have no doubt that at the point where a complainant is able to bring a case under the optional protocol to the UN regarding the operation of Article 19, the relevant UN committee will give a strong steer as to the meaning and importance of independent living.

Q65 Baroness Campbell of Surbiton: Do you think that disabled people and their organisations understand the right to independent living as it relates to domestic calls in this way?

David Ruebain: I do not think they do. On the one hand the legislation, whether it be through the UN convention or otherwise, is very aspirational, and promises a model of inclusion and participation for all, including disabled people. In fact, on the ground, disabled people are finding the position to be very different.

Q66 Mike Crockart: The next question is particularly aimed at Karen Ashton; it is one that you thought was coming, and you were right. You acted in the recent decision against Birmingham City Council, where the administrative court quashed a decision to limit access to funded social care for non-compliance with the Disability Equality Act. This is essentially the question we asked of our previous panel, which you were here for: have you yet formed an opinion as to whether the same decision would be taken under the new public sector equality duty? Does that decision therefore mean that, where it impacts significantly seriously on people with disabilities, a local authority may now be directed to drop a particular funding decision in favour of an alternative that the court considers has a less detrimental impact on disabled people?

Karen Ashton: I will answer the questions in order and hope that does not confuse. I would agree with the answer given by the first panel that the new public sector equality duty is equivalent. Yes, I would hope the same decision would be made. I have a serious concern about the scope of the proposed specific duties in England: as they are currently framed they lead to a reduction in transparency, and they might make it more difficult to identify and challenge failures to comply with the public sector equality duty. For example, under the old public sector equality duty, the specific duties included a requirement that each public authority have an equality scheme, and that they set out in that scheme how they would go about complying with the general duty and how they would go about assessing the impact of policy decisions and so forth on the statutory equality objectives.

The proposal is that the new specific duties will sweep all that away in the interests of reducing red tape—I will go back to that in a moment—and there will be a reduced, at least

in its specificity, requirement to provide information about what the public authority is doing in relation to, for example, impact assessments. My concern is that there will be a reduced transparency, which might make it more difficult to bring a challenge of that kind. I will make one more brief point to that before going on to the Birmingham case. There is a conceptual misunderstanding in the Government's thinking about the new public sector equality duty and the specific duties. The recent review paper has said that their interest is in substantive equality—we would all agree with that—to reduce unnecessary bureaucracy, with less interest in process. But, of course, the public sector equality duty is primarily a process duty, and a very important one at that. I think that conceptual misunderstanding has led to a sweeping away of too much in the specific duties.

I will talk briefly about the Birmingham case in particular. The judgment is very long and it is very difficult to get to what the judge is actually saying about the general implications of the Birmingham case. The court said that the question the councils needed to ask was a whether a critical-only policy was compatible with the public sector equality duty. To answer that question they needed to properly understand what the judge described as the “potentially devastating consequences” of moving to a critical-only policy. Only by having that understanding could they then decide whether they needed to find these less draconian, alternative ways of making savings.

The implication of that judgement is that, although it is primarily a process duty, some policies may be incompatible with the public sector equality duty, and I think that critical-only policies are one such policy. The reason is this: it is difficult to envisage circumstances where local authorities, even in these difficult financial times, will not have alternative ways of making savings that have less draconian impacts. In fact, it was conceded by Birmingham in the course of the case that there were difficult choices, but there were choices to be made. When looking at a move to a critical-only policy, where you are looking at a withdrawal of quite essential community care services, which are fundamental to the promotion of equality of opportunity—the statutory quality objective—it is difficult to see how a council could rationally justify choosing to adopt a critical-only policy rather than the alternative, less draconian method of making the savings. The answer to your question is that it would be very difficult for a council now to move to critical-only and be able to satisfy a court that that was compatible with their public sector equality duty.

Q67 Mike Crockart: That moves us to the next question I was going to ask. We understand there are numerous similar challenges being brought to local authorities in the UK, and some people have argued that there is a real gap—I think that is what you were saying there—between the strategic aim and what is actually happening in practice. In your experience, are you aware of any particular examples of good practice where the two match up far better?

Karen Ashton: To ask a solicitor is probably asking the wrong person, because I tend to see the problems rather than the good practice, and policy people are probably more aware of good practice—

Mike Crockart: We can open up the discussion more widely to other members of the panel.

Karen Ashton: I am certainly aware of better practice in terms of a process for going about making the move; at the same time as Birmingham was considering moving to critical-only, Liverpool was considering moving from a policy of moderate, substantial and critical to a policy of substantial and critical. Its consultation paper was, in my view, more transparent, as it was very clear on the face of the consultation paper what the proposal was and what the implications were. As you are probably aware, the Birmingham case was successful not only

on a failure to comply with the public sector equality duty but a failure to undertake a lawful consultation as well.

David Ruebain: There are a number of examples of public bodies generally using the public sector duty creatively as a tool to drive forward the equality agenda. I know that this is not within the remit of this Committee's inquiry, but certainly in the higher education sector there are a number of that are doing that. However, my particular concern about the new duties is, to take the example afforded by the proposals in Wales versus the proposals for England, the specific duties that we have in Wales under the new public sector duty require public bodies to engage, as has already been mentioned, and to create an evidence base. I am aware that some public bodies are using the duty to create an evidence base to think more widely about what they are looking for—that can include, for example, the requirements of the UN convention—and then to go on to set equality objectives and to impact assess and to prepare a strategic equality plan. The tools available to Welsh public bodies are likely to drive forward the agenda for disabled people, including having regard to the convention. If you take the direction of travel for England, conversely, not only did we have a much more denuded set of duties proposed, but even those were withdrawn three weeks before implementation in March, under the justification that they were too onerous. Although we have not seen what the proposed specific duties in England are—we do not know—the implication is that, in all likelihood, they are to be so “light touch” that they will have virtually no specific impact at all. In that event, while many public bodies will continue to do right by disabled people and others, they will not have the legislative underpinning to encourage them in the way that I have described. I fear very much for the advances that have been made with the public sector duty in England specifically.

Q68 Lord Lester of Herne Hill: You anticipated my question about the specific duties, but that enables me to ask you a specific question, because none of you has had a good word to say about the new regime compared with the old regime. Is the case, which you have not yet dealt with, for having more specific and denuded duties that under the old regime large paper mountains were being accumulated that were incapable of being monitored efficiently, for example, by the Equality and Human Rights Commission? Let us take just the example of London. Under the old regime, the 32 London boroughs, the Mayor of London, the Department for Transport and Transport for London, for example, would all have the duty obligations, and each one would produce its own separate and voluminous, or not so voluminous, documents. They would lie in the cupboard of a body like the Equality and Human Rights Commission as one of many unused documents. Is it not the advantage of the specific duties that are contemplated that they are at least capable of leading to action by the bodies that are meant to do something with them, as well as those who are thinking about it?

The Chairman: Lord Lester, could we have a question?

Lord Lester of Herne Hill: I have asked the question.

David Ruebain: I will be very brief. I absolutely agree that the old specific duties were not perfect, and I am not sure that anyone was collecting any of the documents in the way that one fears. I agree that in some respects there was an emphasis on process over outcome. I fear that in short we have gone the other way. I think that there are tools that could be used from the old duties which lend themselves very well but are not being adopted. The other big positive about the new duty, it should be said, is that it covers more than just three protected characteristics, but of course we are here today to think about disability.

Q69 Baroness Campbell of Surbiton: Outside the public duty, can and should the UK Government, the devolved Governments and local authorities assess the impact of proposed

policy changes or funding cuts on the right to independent living before they are implemented? If you think so, I wondered if you thought the Government has taken adequate steps to monitor the impact of policy changes and cuts to funding on disabled people and their right to independent living. If not, what should they have done?

Pauline Thompson: I think one of the difficulties is the whole tension that you see in the Government’s vision for social care, which is littered with references to living independently yet makes no mention whatsoever of the Article 19 rights but just generally puts them there. So often you hear, “Well it is the local authority’s decision, and local authorities do not need to cut because they did have the money”. You are in that double bind at the moment. I think to actually see how much it is affecting, when there is so much denial going on that it is affecting disabled people, is a very difficult situation.

Q70 Baroness Campbell of Surbiton: What steps should the Government be doing to take independent living forward? You said they are not doing anything and that it is all rhetoric, so what should they be doing?

Pauline Thompson: I certainly think that they should be offering far more advice from a departmental view. As I say, the Office of Disability Issues is issuing all its guidance, but that does not get through to the people that are actually commissioning services. For instance the ODI recently did a survey of older people in care homes and had some commissioning recommendations, but it was not put on to the Department of Health’s website nor were the commissioners actually told about it. It is a question of there being much more leadership from the departments. We know that local authorities do have difficult decisions to make, but I think there should be much more leadership as to how they could go about thinking about it in the round as well. We are not just talking about social care. That is the one that is most obviously affecting disabled people, but with all of the other departments there is the cumulative effect.

Q71 Baroness Campbell of Surbiton: That leads into my second question. Disabled people’s organisations have told us that the impact of the Government’s proposals to reform the benefits system together with the cuts to funding will lead to a breach of Article 19 of the convention. Do you agree with that conclusion? If so, is there a particular proposal which you think will violate the convention, and why?

Diane Mulligan: As I stated earlier, Article 19 needs to be looked at in relation to other articles within the convention, some of which have been touched on. For example, Article 28 is around inadequate standards of living and social protection. A lot of the new reforms that are being proposed are around social security and social protection issues. Article 12 is around equal recognition before the law. Currently we have a reservation on that article as well as a lack of clarity about whether the Mental Capacity Act is actually compliant with the convention. It also relates to many other articles of the convention, in particular if there are violations of other human rights—for example in employment settings, through transport, healthcare, housing, education and attitudes et cetera. They all intersect and impact on the right to live independently and to live with dignity as part of the community.

In some of the proposed changes—and I agree with the previous evidence that Baroness Campbell refers to—for me there would be a clear breach of Article 19 through the accumulation of a proposed number of different cuts, some of which have already come into effect, such as the closure of the independent living fund and the lack of a clear independent living strategy that was put in place in 2009—there is no clear status on that report at the moment. The reform of disability living allowance is proposing a cut of 20 per cent of its budget in the new personal independence payment. On the special educational needs Green Paper—the consultation for which was not even available in an accessible format—we have

an Article 24 reservation that relates to independent living, in as much as children educated outside their own community could intersect with that. Currently, looked-after children have no independent right to appeal against their special educational needs statements so, in terms of their right to living independently and live in the community, that too intersects.

Baroness Campbell, there is no specific right to the portability of care packages at the moment, which is an issue that is close to your heart. On the disability living allowance higher-rate mobility component, the proposals that are being reconsidered at the moment—and I have undertaken a number of interviews with people in residential care settings about these proposed changes and how they would be affected—could affect over 80,000 people in the UK. Because of the eligibility criteria and the changes to social care, one gentleman I interviewed was not able to continue to live at home because his care package had been cut at the weekend; it was in place during the week. His wife tried to provide the care for him at the weekend but became exhausted and had a breakdown, so he moved into residential care. He has young children at home, as well as grandchildren, and his only way to maintain his independence is through his Motability adapted vehicle which he exchanges for his disability living allowance higher rate. People like him will be directly affected.

In addition there are reforms around legal aid, and there is the realigning of support for mortgage interests payments that have affected a disproportionate number of disabled people who are living in adaptive homes and have had to move. Regarding the reduction of local housing allowance and the capping of housing benefit, around half of all private households in the private sector claiming housing benefit have a disabled member. The availability of community care grants and crisis loans are disproportionately affecting disabled people too. For me, I would like a human rights approach to the impact assessment of how those changes are going to affect disabled people in the UK.

Pauline Thompson: We have not mentioned carers and the effect that some of these cuts will have. Family carers will have to take on so much more care and therefore you are making people far more dependent on their family carers than they have had to be in the past when they have been able to get services.

Q72 Mike Crockart: You have given a long list there of things you think are potentially impacting upon the disabled. I think it is generally accepted that the UK has had a good record on disability issues in the past. Do you think that what is happening, with the list that you have given, does actually raise a serious risk that the UN will criticise the Government for its performance? If so, what do you think the implications of that would be?

Diane Mulligan: It is a long list. I think the UN expert committee will take that list—presumably provided in some sort of shadow report or parallel report provided by either the independent mechanism or disabled people’s organisations—and I am sure it would look very carefully at all of those different proposed changes in the round and look not only at a potential breach of Article 19 but the other breaches that I mentioned, such as the right to adequate housing and social protection, which is better known as social security in this country. The UN expert committee could issue advice to change that within a particular framework and timeframe. As Duncan mentioned earlier, these are around progressive rights and progressive realisation, but we need to bear in mind Article 4(2), in that there must not be any retrograde steps and maximum resources must be allocated. This is a clear indication that maximum resources are actually being reduced rather than provided for independent living and living in the community.

Q73 Lord Lester of Herne Hill: Are adequate mechanisms in place to ensure and inspect the right to independent living across the different countries of the UK and across local authority boundaries?

David Ruebain: I have already mentioned my view about the divergent approach to the operation of the public sector and the new public sector duty. We do not have the specific duties for Scotland yet, but the indication is that they will be fairly robust unlike, in my view, the indication for England. The ones for Wales are pretty robust. Incidentally, I hope they will avoid some of the difficulties that Lord Lester has raised regarding the operation of the old duties. Northern Ireland obviously has a separate set of arrangements. The other thing I would want to say about the different approaches in the four countries is the anecdotal information that the approaches of the different jurisdictions afford different levels of importance to independent living. That may or may not translate into action and in many respects it is too early to say yet because certainly with the elections that have happened recently we are still waiting to see what impact the new Administrations will have for disabled people. It may well be that we will see a more divergent approach in the coming period, so a range of things including opportunities for disabled people to live independently.

Karen Ashton: I just want to pick up on the issue you are raising. Across local authority boundaries there is huge variation in very small geographical areas. If you go across local authority boundaries, you may face a completely different eligibility policy for community care services—there will be a different charging policy, a different cultural and institutional approach and different political colours of the administration. That impacts very directly on very basic elements of independent living, which is choice about where you will live—very much part of Article 19. Those barriers of localism should not be underestimated. There is a proposal or recommendation by the Law Commission to include in any new community care legislation a power for the Government to make national eligibility criteria for community care services through secondary legislation. At the moment I think it is a bit unclear whether or not that is going to be taken up. Of course, although it would be counter to localism, that could help enormously on the barriers caused by that very close geographical variation.

Q74 Lord Lester of Herne Hill: What I am not clear about from what you have said is how much scope the convention allows for localism and diversity within a member state.

Karen Ashton: I think it is a real problem because it is not a directly enforceable right. It does not directly constrain through the legal framework the choices that are made within that locality. It allows for huge variation; that is the problem. I think there is a real tension there.

Q75 Lord Lester of Herne Hill: Turning to Article 4(3) of the convention, the duty to consult and involve disabled people in forming law and policy, do you think that the Government and local authorities are currently meeting that obligation? If not, can you give examples of their failure?

Pauline Thompson: I point to the example of the independent living fund, which was to all intents and purposes closed last year and suddenly ended for new applicants. I cannot say that there was much consultation on that. Regarding the equality impact of the change, it just said that to make no offers on funding will have an adverse effect on all equality groups, and then said, “We must get round to asking the local authorities”. They assumed that the local authority would be able to pick this up, but of course local authorities were facing cuts at the time. They had not even consulted with local authorities let alone disabled people.

Q76 Lord Lester of Herne Hill: On the other side of the coin, perhaps this is a stupid question perhaps but what do you think Governments should then be doing positively to encourage compliance with Article 4(3)?

Pauline Thompson: I certainly think they should be really making it quite clear—this is their own department—that you absolutely must do the right amount of consultation and make sure that they are aware that they would be in breach of their duties on the consultation issue.

Karen Ashton: I do think that, with the current general theme of Government policy of doing away with red tape, the problem is that what can be drawn into that are very important elements of process such as consultation with people with disabilities, which actually requires a lot of careful thought and resources to ensure proper inclusion of people with different kinds of disabilities that affect them in different ways. For example, what would be required in terms of consultation process for a deafblind person would be very different to that required by somebody with autism. My worry is that an overarching theme of “Let’s reduce bureaucracy and red tape” may perhaps unintentionally adversely impact on consultation. I think the Government has got to be very careful to distinguish between essential elements of process like consultation of this kind and unnecessary red tape. It is a baby and bath water scenario.

Q77 Baroness Campbell of Surbiton: Diane, you have already told us that disabled people have not really been effectively involved in the preparation of the UK’s periodic reports to the UN and the work of the national implementation mechanism. What should they have done? What could they have done? What should they do in the future?

Diane Mulligan: The Government do involve disabled people through some mechanisms currently. One of those is Equality 2025, of which I am a member. They have a working group on the convention but it is made up primarily of large disabled people’s organisations that do not fully represent disabled people. For me what the Government should be doing, if I may say so, is to be developing a framework for action for the implementation of this convention, involving disabled people from the outset. They are about to submit their report this year and there is not a national plan of action in place. It is not clear, either, whether the new disability strategy that is coming out from the Office for Disability Issues will promote, monitor and implement the convention with the involvement of disabled people. I suppose that is particularly worrying. Did you ask about the independent mechanism as well?

Baroness Campbell of Surbiton: Yes I did.

Diane Mulligan: On the independent mechanism, you had evidence earlier from Mike Smith who is the Chair of the Disability Committee; so that Committee is involved. There has been a number on stakeholder engagement events around the convention—I think seven in total—as well as a guide written on what the convention means to you. There have been some grants for a Scottish independent living project as well as an expert panel on the convention. Currently there is an inquiry into older people’s rights and care and support at home. It has also supported a number of legal cases but you can always do more to involve disabled people. I think the major issue in the UK is that disabled people do not know about the convention, our legal professionals in the country are not up to speed with it and the Government does not fully understand its obligations under it.

The Chairman: On that critical note, I will bring this session to a conclusion. I thank you all very sincerely for all your evidence. Some of you have spoken both eloquently and long. I recognise the importance of that subject, and I am not criticising you for that, as I welcome the comprehensive way in which you have answered the questions. If, however, you feel that we have not adequately covered anything, please feel free to write to us. We will certainly be writing to you not only to thank you but also to ask a few more questions.

**Professor Peter Beresford, OBE, John Evans OBE and Doug Paulley;
Stephen Lowe, Emily Holzhausen, Andrew Lee and Marc Bush**
Oral Evidence, 28 June 2011, Q 78–106

EVIDENCE SESSION NO. 3. HEARD IN PUBLIC

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

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 different things. 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, and has enabled me to work—I have worked regularly—and Independent Living has given me 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 gives me the freedom of choice. It is the freedom for me to be able to do what I want to do, when I want to do it, in my individual 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 and services 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 control and 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 alone.

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 as 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 they would then be part of a process of restraining the chance of those adults to have 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, this was done in co-production with 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 also a need for joined-up thinking and there is probably a need for more specific 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 areas 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 Pauley: 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 in a legal 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 Pauley: 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 a very personal level 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 independence 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.

**Lorraine Gradwell, Julia Lim, Kate Sheehan and Tracy Hammond;
Tracey Jannaway, Hazel Roper, Nadra Ahmed and Adam Penwarden**
Oral Evidence, 5 July 2011, Q 107–171

EVIDENCE SESSION NO. 4. HEARD IN PUBLIC

Members present:

Dr Hywel Francis (Chairman)
Baroness Campbell of Surbiton
Lord Morris of Handsworth
Baroness Stowell of Beeston
Rehman Chishti
Mike Crockart
Richard Shepherd

Examination of Witnesses

Lorrain Gradwell, Breakthrough UK, **Julia Lim**, College of Occupational Therapists Specialist Section: Housing, **Kate Sheehan**, College of Occupational Therapist Specialist Section: Housing, and **Tracey Hammond**, KeyRing.

Q107 The Chairman: Order, order. Good afternoon and welcome to this evidence session of the Joint Committee on Human Rights into our inquiry on independent living. For the record could you all introduce yourselves please?

Lorraine Gradwell: My name is Lorraine Gradwell and I am from Breakthrough UK Ltd.

Kate Sheehan: I am Kate Sheehan from the College of Occupational Therapists, the Housing Section.

Julia Lim: I am Julia Lim from the College of Occupational Therapists, the Housing Specialist Section.

Tracy Hammond: I am Tracy Hammond from KeyRing.

Q108 The Chairman: Thank you very much. Could I begin by asking a very straightforward question? We have received a great deal of evidence from individuals and organisations about the importance of independent living as a basis of Government policy. Could you explain in your own words what you mean by independent living for your own organisation and for the individuals that you represent?

Lorraine Gradwell: Shall I start?

Q109 The Chairman: Please.

Lorraine Gradwell: Okay. My organisation is an organisation that is controlled by disabled people, so our view on independent living comes directly from disabled people themselves. It is quite simple in our eyes that it is about autonomy. Independent living is about being in charge of your own life and making your own decisions. It is not about not needing

support—that is a fallacy. Everyone needs support, in their daily lives, of one kind or another. But it is about being in control of that support and having the final say on what kind of support you get, how it is delivered and who it is delivered by.

Julia Lim: I got up this morning; I went to the toilet; I had a shower; I left my home; I got the train to come here and I met with my colleague Kate to have a coffee, all without a problem. I would expect, as a disabled person acting as a full citizen, to be able to do exactly the same thing without having to worry about how I would be doing that. That is our understanding of independent living.

Tracy Hammond: We think that independence is very different from isolation and that is really key to everything we do. We believe it is about neutrality; it is about community, choice and control, so that people are actually able to choose which parts of the community they become involved in at a time and in a way that suits them.

The Chairman: Thank you very much.

Q110 Baroness Stowell of Beeston: Hello, I am Tina Stowell. I would like to direct my question to you Ms Gradwell, representing Breakthrough. When you consulted with disabled people to draw up your written evidence they told you—and I am just going to quote from your evidence—that they “did not feel that they were afforded the same rights as non-disabled people and there were significant gaps between how they want to live and how they are living”. I wondered if you could tell us, by providing examples, what kind of experiences they were talking about in making that comment? Do you think the Government’s Independent Living Strategy is addressing their concerns?

Lorraine Gradwell: Breakthrough is an employment support organisation that supports people towards independent living. So a lot of people’s experiences revolve around employment, skills, education and training. People struggle to get access to the same education as their peers; they struggle to get access to skills development and career development, and they struggle to get access to employment. They clearly felt that there were rights in there that non-disabled people had that they did not have.

People also talked about things like a right to life, which disabled people do not have. We see selective abortion, for instance, targeting foetuses with impairments. That is targeting disabled people to eliminate them. People talked about the right to medical treatment, and people I know have had “Do not resuscitate” notices put on their files because they are disabled people and there have been assumptions about their quality of life.

I do not think I need to say much about the right to freedom from torture or cruel, inhuman or degrading treatment given the recent publicity about people’s experiences in care homes. There is also the right to personal mobility, as my colleague here said. My trip here today was really very much the same and that is a really good example of how independent living can be made to work.

So, is the Government’s strategy addressing these issues? I would like to quote from the Independent Living Scrutiny Group’s second annual report. That says, “As we move to the midway point of the five year strategy, we would expect to be seeing indications of the positive impact of the action plan. Unfortunately this has not really been the case”. I think that answers the point as to how things are happening. It is not to say that nothing is happening but I do not think it is standard enough across the country. Disabled people still experience a postcode lottery and it is hard for my organisation to see a report on the progress the Government thinks it is making towards independent living and actions to fill the gaps.

I think the Independent Living Strategy should be ensuring that we do not have to fight for each and every right. That is what people are telling us they have to do.

Baroness Stowell of Beeston: Thank you.

Q111 Baroness Campbell of Surbiton: Hello, I am Jane and my question is for Tracy Hammond and your organisation KeyRing. Just looking at your written evidence I saw that you clearly stated that “the difference between isolation and independence is clearly enshrined in Article 19”. I thought that was good, especially when it discusses the right to community life. Could you tell us how you think this difference plays out in practice and also what contribution the current Government policy makes to the right to community life?

Tracy Hammond: I would just like to give you a couple of examples. We have a number of service users who come into KeyRing having received very little support in the past, or having received floating support where somebody is actually being parachuted in to come and do a piece of work with them for a few hours, and then has left. That person may or may not have good links with that community. By building a network of people around that individual, and placing a volunteer whose remit it is to support that person to make links with the community, we find that we can support people to have real relationships. That is the first thing. Rather than having a community presence to say, “I use the leisure centre”, it is very much about having real relationships with people who are not paid to be in your life. That is really the first bit. That is the difference between isolation and independence.

The other thing about that is that it is very important for somebody to have choice around how they engage with the community and that is going to look different for everybody. Everybody has different skills and talents to bring. We would actually be looking not just for someone to go in and use the community but actually to take things to the community and to share those. A lot of our members will help local people out with their shopping and in return they will perhaps get a meal or be invited round to their house, et cetera. So it very low key, local community things.

Some of the things that can sometimes get in the way of that are the way we still tend to think in silos. Sorry, is this answering your question?

Q112 Baroness Campbell of Surbiton: It is. We will come to Government policy in a minute. But keeping your head on policy, what is it doing to contribute to community life?

Tracy Hammond: At the moment, things around Big Society are actually giving emphasis to community life. What is happening at the moment with the personalisation agenda and that kind of thing is really drilling down and looking at what people really want from their life. The problem is that it is going to be a different answer for every individual. Sometimes we lose that when we are trying to support people through the policies.

Q113 Mike Crockart: I have another general question, aimed more at the College of Occupational Therapists. You submitted written evidence—thank you very much for that—and in that you stated that “the UK should be proud of the national framework of legislation and practice guidance that has developed over the decades to support accessible housing for people with disabilities”. Could I ask you to expand on that and give the legislation and practice guidance that you have in mind, and say how that has contributed to delivering independent living?

Julia Lim: The key point for us is that any right only becomes an accessible right once it is enshrined in law and protected by that status. We outlined three areas of legislation and guidance in our written evidence. The first was assessments, the right to assessments and consistent assessment. I do not know if you want me to repeat some of the legislation that we talked about in our written evidence?

Q114 Mike Crockart: In brief yes. Let us get it on the record.

Julia Lim: The Chronically Sick and Disabled Persons Act 1979 actually introduced a duty to assess and make practical arrangements, which was then reinforced by the NHS and Community Care Act in 1990. There was the Carers (Recognition and Services) Act 1995 that looked at assessing the needs of carers of people with disabilities later on.

Then we looked at the area of provision following on from assessment, looking at the fact that legislation means there is a duty to provide on the basis of assessment, to provide access to an essential facility, which the Housing Renewal Grants Regulations of 1996 brought in. That is the basis of disabled facilities grant provision of adaptations.

We also looked at the basis for community engagement and contribution. That is because thinking about independent living is about involvement and not isolation; if you cannot get yourself ready for your day, cannot get yourself out of your home or do the things that you need to in your home then you cannot start being part of your community and you will end up trapped in your home.

The final raft of legislation that we looked at was legislation that affects planning and housing supply requirements. This relates more to looking at thinking for the future and providing new housing that is actually suitable for current and future needs. The Town and Country Planning Act introduced Section 106 conditions that local authorities could place on developers, for example to require them to build a certain proportion of accessible housing in their developments. That has been key to raising the amount of purpose-built accessible housing stock across the country and has been built on by the Greater London Authority in developing its supplementary planning guidance and the London Plan, with OTs.

There has also been guidance to local authorities on how to allocate their housing stock equitably, how they develop and how they use the choice-based lettings systems, all of which affect the potential for social mobility for people with disabilities. You could potentially have your home adapted for your needs. But it is really important if you are in work to know that if your job changed place you could actually move to your new job and expect to find suitable housing there as well. Has that answered your question?

Q115 Baroness Campbell of Surbiton: My question is to Lorraine. In your written evidence you say that Article 19 is only one aspect of independent living. It should be looked at holistically alongside the other articles in the UNCRPD because they are interrelated. You also say that discrimination in employment was a substantive concern for quite a number of disabled people with whom you consulted. So what contribution do services such as Breakthrough make towards the fulfilment of disabled people's rights under the Convention, and can you give me some very practical examples of where the services you provide have assisted disabled people into employment and thus enabled them to access this thing we call independent living?

Lorraine Gradwell: Yes I think so. The first thing to do is to define holistic. Disabled people do not live in silos: we get up, we have a life and we go to bed, hopefully, and we need what we need in-between that. We have operated an independent, arm's length advocacy service that puts the disabled person at the core of the process. Although the focus of that advocacy service was employment it actually dealt with all the other issues that might be around that in terms of helping people to get in work, to stay in work and to get on in work. That support service would support people to identify their own desired outcomes and then either signpost them to where they could get the support or provide the support if there were no agencies available, because a lot of agencies do work in silos. They would also provide ongoing support, and that bit is vital.

I can best illustrate it with one particular case study of a young man who was referred to our project. What is interesting is that, of all our referrals at Breakthrough, about 50% of them are word of mouth and do not come through any statutory agency but from someone who

knows what we do and has recommended that they should go and see Breakthrough. Anyway, this learning disabled guy was actually working full-time and rubbing along nicely and then all of a sudden things started to go wrong at work. He started not showing up or he would show up a bit the worse for drink and his performance was going down. His job was in danger and someone said that he should go and see Breakthrough. It turned out that what had happened was that his support in order to hold down his job and live his life had been his father and his father had died. So he did not have his father to keep him off the drink or to help him get to work. He was also getting into trouble with the housing authorities and he was falling into debt. As an organisation we were able to help him across all those issues to help him keep his job. The job was the focus, but we got him into bereavement counselling, sorted out his transport to work, helped him to negotiate around his debts and helped him sort out his housing to replace the kind of support he had had from his father. So I think that is a really good example of the way that something that is ostensibly employment focused can widen out and address a whole range of issues that, if not dealt with, will threaten people's ability to stay in work.

Baroness Campbell of Surbiton: Thank you.

Q116 Rehman Chishti: I would like to ask another question to Breakthrough and Lorraine. Do you consider the current legislative and policy framework to be adequate and effective in enabling employment support services to play their part in helping disabled people access independent living?

Lorraine Gradwell: No I do not, mostly because of the things I have just said. Even though the Government's current work programme is a kind of black box, whereby they pay the providers to achieve the outcomes, most big providers do not know how to work in the way that we work. They are not guided by disabled people's influence and do not have that experience. Some 60% of my staff are disabled people. We know what we are talking about—we are all working. It is a real pity that in the Government's current framework for employment support there was no reference to things like employment advocacy that takes an holistic approach and there is not a push for the prime providers to be looking at that. It is quite an unusual project. To my knowledge it does not exist anywhere else in the country. Unfortunately it does not exist in our organisation any more because the funding ended in October.

Q117 Rehman Chishti: I would just like to clarify one thing if I may, Chairman?

The Chairman: Yes.

Rehman Chishti: It is with regard to the point you raised earlier about the aim of the Government to pay by results being a good aim but there having been problems with providers putting it into practice. So the wider aim of the Government is right but there are issues with the way it has been put into practice—is that right?

Lorraine Gradwell: I would agree with that, and I would add one particular element to it. What we are seeing is that most of the prime providers are private contractors and where they are third sector providers it has been quite hard for them to get into a position to do that. Very few, if any, are user-led organisations such as ours. It is quite a difficult process to be a part of, and I think that is a major gap in Government policy.

Q118 Lord Morris of Handsworth: My question is to the representatives from the Specialist Section of the College of Occupational Therapists. Do forgive me for quoting back your own evidence, but it sets the context. You state in your written evidence that current policy proposals “run the risk of substantially reducing the rights of disabled people to independent living through the possibility of unintended consequences of interacting

cumulative impacts”. A couple of questions flow from that quote from your statement. The first is this: what specific policy proposals do you believe will lead to these unintended consequences?

Julia Lim: One has actually happened and is no longer just a proposal: the private sector renewal grant funding stream was stopped as part of the comprehensive spending review. That funding stream enabled quite a lot of imaginative work around enabling housing adaptations, or alternatives to housing adaptations, to take place. This included repairs work, support for people to move to an alternative property that could be adapted if their own could not and emergency repairs grants. That funding stream is no longer there so those kinds of provision are already being reduced.

There are proposals to change the provision of housing benefit—to put a cap on housing benefit and potentially impose penalties by restricting housing benefit for people who are deemed to be under-occupying their property. Imagine that you are a woman living in a two-bedroom house, which you have had adapted for your disability needs, but are now living in that house on your own and are reliant on housing benefit. If the cap penalty is introduced, you then have to think: can I move to another adapted property that is within my area and close to my support network? Can I afford to do that? Is there a property? Or will I need to remain at home and think about whether I pay my rent or heat my home? Those are the kinds of impacts that there may be for people who have either already had their homes adapted or are needing to have their homes adapted but have local networks they need to stay within reach of to remain independent.

The Localism Bill proposals also raise some concerns in respect of planning arrangements. The whole basis of the Localism Bill is to bring decisions down to a local level and remove what is perceived as the burden of central directives. The concerns we have about that are that disabled people are generally in a minority in the population and they are not always a very visible part of the population. Are their needs actually going to be considered by local decision makers when balancing the need to generate income and meet new build housing requirements? Things like Section 106 are a way of ensuring these needs are still borne in mind and made a reality.

We are also concerned about proposals for social housing. The proposals are to introduce flexible tenancies, which would be of a shorter length, and to offer housing providers the freedom to increase their rents to 80% of market rents with no indication as yet of whether disabled tenants will be exempt from any of these provisions. It is well known that disabled people are far more highly represented in social housing than any other group, and higher numbers live in social housing. You are far more tied, even with what we have said about the developments in planning that have meant there is more purpose-built new-build housing. If you have been through the disruption of having your home adapted you do not want to have to move again and see whether you are going to find another property that is adapted if you have a flexible tenancy that potentially comes to an end.

Those are the main concerns that we have. We have members who work in housing but based within health or social care and we can see how all of these things actually come together to create real problems.

Q119 Lord Morris of Handsworth: Thank you. You have informed us well in respect of single free-standing issues, whether housing or otherwise. That is quite clear. As I indicated when I quoted your evidence you are also concerned with the cumulative impact of the issues. Can you provide some examples for us as to how these cumulative impacts adversely affect the lives of people with disabilities? Is it just about money, or are there other underlying problems?

Julia Lim: It is difficult at this stage to provide live examples because so much of this is currently proposal and we do not know what will actually happen. A lot of it is about money. Some of it is actually about issues on how we think about and design our housing. That is not necessarily about money. It is about good planning, thinking about the housing needs of all of us and providing housing that is accessible. It is not just housing that is suitable for people with disabilities but thinking about something like the lifetime homes standard, which was developed precisely to give us housing that could meet a whole range of lifetime situations—for example, someone who has a child and needs to manoeuvre a buggy around the place, someone who might break their ankle playing hockey and be temporarily less mobile or someone who is becoming older. Those sorts of things are not just about money. They are about forward thinking and future proofing. If there are constraints on funding or freedoms to make local decisions affecting planning that mean these disability issues and planning issues are not considered they come together to really reduce the amount of choice that is there for disabled people in where they live and how they live.

Q120 Lord Morris of Handsworth: The housing standards are, in essence, good practice. Is there any case for saying that there should be mandatory regulations about access sizes or that sort of thing?

Kate Sheehan: I would strongly propose that any housing standards are mandatory on the grounds that even under Part M of the Building Regulations you still find developers who do not actually adhere to the regulations, but at least then you have a way of saying something has been done wrong and it should be changed or adapted. When something is good practice the developers will always go to the minimum standards. So you need your minimum standards to be at least of a standard good enough to meet the needs of people now and into the future. It is not just about people with disabilities; it is about good design. If we are a more inclusive community, we are not talking about different groups such as parents with children, people with disabilities or older people but developing a community that is a lifetime neighbourhood. It has to be better for society to produce something that meets all our needs regardless of our abilities.

Q121 Baroness Stowell of Beeston: Your last remarks segue nicely into the next set of questions, which are in the context of the Government's efforts to reduce the deficit and reductions in spending. What they have told us in their evidence is that, although there will be difficult choices to be made in tackling the deficit, they intend to ensure disabled people with the most difficulties are effectively supported to live an independent life. They stress that securing an independent life is not all about money. You have talked a bit about planning. My question is: do you agree that meeting the UN Convention is not all about money? You have already talked about planning but there may be other things you can tell us about that demonstrate that it is not just about money in ensuring that we meet the Convention in terms of rights for independent living. That is a general question that is open to any of you to respond to.

Lorraine Gradwell: Can I go first?

Q122 Baroness Stowell of Beeston: Go on.

Lorraine Gradwell: The first point is that it is not just about money but it can be about how you spend the money. I would refer the Committee to a report produced by the Office for Disability Issues a few years ago called Better Outcomes, Lower Costs, which showed that, where money is spent sensibly in a preventative way in certain areas, the long-term impact is to reduce costs and also probably to promote good mental health and wellbeing. So I think

that is really important and the focus on prevention and early intervention is probably cheaper anyway and it certainly has long-term benefits.

The Government needs to be congratulated in one sense in terms of its support to user-led organisations in its recent initiative. However, we need to be seriously building the social capital of disabled people and the user-led organisations because nothing works as well as peer support. Obviously you need the appropriate professional advice and intervention but there is nothing more valuable than someone who has been there, done it and got the T-shirt. I have known of people who have very simple adaptations—for instance door openers that you can make at home—rather than a big expense. There is a theory, which is maybe a bit dated, called “calipers in the cupboard”, which says that, for every disabled person, there is a piece of equipment that is not used. Now that is a great loss to lots of other people who could either use that or a different kind of equipment.

To go back to the point about peer support, with the right peer support a lot of disabled people will find their own solutions and will share those solutions. That is of no cost and is also building a social capital. The kind of capacity building that our organisations need is vital to independent living because we can provide that support, we can provide that advocacy and we can help build it in other areas, which is one of the things that my organisation is doing.

Q123 Baroness Stowell of Beeston: Thank you. Does anybody else want to add to that?

Kate Sheehan: For us early intervention is key and there is a huge wealth of evidence out there that proves that early intervention actually has a huge impact on people’s health and wellbeing. I can give you a wonderful example of a young lad in our local area who had a road traffic accident and lost a limb. When he went home he wanted to return to school but he could not because he could not get out of his house, purely for lack of a ramp. He was told the waiting list was 18 months because outside access is not a priority. For that young man it was critical. He wanted to go on and do his GCSEs but what his parents were doing was physically carrying him outside, putting their health and their backs at risk, for want of something that costs £800. Actually, you could have put something in temporarily because that young man is now on a prosthesis and walking, and so does not need it. It seems that early intervention, getting in there and doing that quickly would have made such an impact on that man because he would have been back at school, back with his peers and back in education. His family home would be promoting independence and inclusion, and that would have been a far better way.

So early intervention is really key and it is cost effective. Waiting 18 months for outside access or a bathroom has a huge impact on people physically and psychologically.

Q124 Baroness Stowell of Beeston: In a case like that, where would you place responsibility for the fact that that happened—that the young man did not get his ramp?

Kate Sheehan: On the fair access to care legislation. Fair access to care was saying that this was not a substantial need so it would not be met under social services. So he was not actually eligible for assistance. If all the organisations had worked together, with education, social services and housing working together, the costs would have been minute, but the impact on that young man was huge. That was my next point—we have to work cross-departmentally. As OTs we work across health, housing and social care and we spend time being so frustrated, trying to work with housing providing one bit, social care providing another bit and health another. It is constantly a battle whereas, if we could work together, it would cost less. However, everyone protects their own money rather than thinking what an individual needs and how to move it forward.

So I think cross-departmental work is important. A wonderful example of something like that is the housing service in Brighton which has an occupational therapist who is funded by housing, but works very closely with the local health authority on planned discharges. So if minor adaptations are needed then they are in within 24 hours. If a housing need is highlighted very early on they can see what they have coming up, what new builds there are or what is becoming vacant. So they are constantly thinking and they know what is happening in their own department that might meet a health need, so you are saving money on discharge costs. That has worked tremendously well.

Baroness Stowell of Beeston: Thank you.

Q125 Lord Morris of Handsworth: I just wanted to pick up on a point that Lorraine made. You obviously place a very high value on the concept of social capital. You repeated it a couple of times. Could you define it for us and tell us how you measure social capital?

Lorraine Gradwell: I would need to write a book. I just think social capital is about how people are able to grow and develop in their own locality and in their chosen occupation, whether it be paid employment or not. Social capital can be applied to individuals; it can be at a very basic street level, ward level or neighbourhood level. How you measure is very difficult. There is a need to define what aspects of social capital we are looking at and how the social capital of disadvantaged groups—

Q126 Lord Morris of Handsworth: I want to understand how it can help independent living, which is our terms of reference.

Lorraine Gradwell: Okay, I think it can help independent living by ensuring—if it is prioritised, measured and acted upon—that disabled people are a part of the community. It links to the worries expressed about the Localism Bill, about whether or not disabled people's issues are being addressed and whether or not disabled people are actually in there talking about it. People are excluded, whether we like it or not, and it is very difficult for people to be involved at times. That is how the social capital issue and the measurement and development of social capital links to independent living. Independent living is about being part of your community.

Q127 The Chairman: Tracy, did you want to say something?

Tracy Hammond: Yes, I would just like to pick up on the issue of social capital. The first thing I was going to say is that it is not all about money; it is about using the support to try and release the social capital that is available within the community. For us, that would be supporting people to make links where there is some degree of mutuality, where there is some mutual support going on—so where somebody who has traditionally been seen as a service user becomes someone who is actually involved in the community and becomes almost a community leader in many respects.

It can be about peer support. We work in networks where our members are briefed to support each other and they do that through volunteering. So again we have social capital within the volunteer role. So there are an awful lot of things sitting there in the community that just need unlocking. For that we need—community activist is probably too strong a word—people who are good at making ordinary links. I would refer the Committee to the work of John McKnight, which I am sure you are familiar with.

The other thing I think would be really helpful in ensuring it is not all about money would be looking at how we spend the money we do have. With some of the housing policy that looks like it might be coming through at the moment, it is likely that people are going to have to move and relocate. If this happens, it is also possible that they will lose their social networks and that could end up costing us more in the future. At the moment it is not within social

services to assess different costs associated with two people in different locations. For example, if somebody has to move to find cheaper accommodation it could actually mean that they lose contact with their friends, family and neighbours who have provided a lot of informal support. It could end up costing us more to provide that support. So looking at location-based costs, rather than the silo thinking that is going on at the moment, could be a way forward.

Q128 Baroness Campbell of Surbiton: The question for all of you is, in light of the proposals in the comprehensive spending review, do you think that there are any specific changes to Government policy which could better promote employment and housing opportunities and better the UK's obligations in the UN Convention without increased funding? Who wants to start?

Kate Sheehan: Lord Morris talked about better design standards. I think if we can look at it in various ways but have better designed housing for our new houses to then meet the needs of our population, not only people with disabilities but also our ageing population, then we will have better properties. If we look at refurbishment, certainly under the decent homes programme accessibility has not been a key integral part of it. What is happening is that those things are not being addressed at a time when refurbishment is happening and actually it could be a nil cost gain. A wonderful example of this is the ripping out of front doors that are level thresholds and putting in UPVC doors. Yes, from a sustainability point of view these keep in the heat but they keep people out; it keeps people either trapped inside their house or people cannot visit them. Actually you can get extremely good UPVC doors with threshold level.

It is about thinking a little bit in advance when doing refurbishment and maybe spending just a tiny proportion more that will save you a huge amount in the future. For example, putting a level access to the shower under a bath, so you can take it out quickly if somebody needs it and you can put a bath back if a family needs a bath. It is about thinking about good design that will meet all our needs.

One thing we have real issues with is about the quality and standard of rented accommodation. You just need to look at the report from the BRE and Warwick University that said that they think poor housing costs the NHS £600 million per year. Actually, if we address poor housing, we can have a major impact. The problem is that people who have disabilities tend to live in poorer conditions because of the nature of their employability and the fact that society unfortunately treats people with disabilities differently. I fundamentally believe that if you get good housing where people can get in and out and use it appropriately they can then start to be engaged in work, education and leisure and can become economic citizens, which is a horrible phrase, but they can become engaged in their community. We need to promote that as part of independent living.

Q129 Baroness Campbell of Surbiton: Lorraine, what about employment with no cost?

Lorraine Gradwell: Again I am going to talk about user-led organisations, disabled people themselves and using the existing organisations to work with employers to demonstrate good practice. My organisation employs a minimum of 50% of disabled people and has done for 15 years and it is really not a problem. There needs to be a way of working—probably on a local level, building relationships with employers—and the best people to do that are disabled people. Also, to go with the issue of how we use existing money, we need to be making sure that our organisations can be commissioned to provide employment support. This means the results are better. People stay in work longer and we work with people who are further from the world of work. I think the results speak for themselves.

There are a couple of other things I think should be done. I think the Independent Living Strategy could be refreshed to give it some teeth. That covers things to do with employment, skills and so on. One of the big issues, and again this could be done within existing resources, is tackling institutional resistance to change. Certainly with the work we have been doing on the right to control, one of the biggest issues we are coming up against is a resistance to change—not necessarily deliberate, but still a resistance. As long as that is happening within all our institutions that is going to be a problem. Could I just add a point about the housing situation?

Q130 Baroness Campbell of Surbiton: Yes.

Lorraine Gradwell: None of that is about private housing, which is the other side of it. For those of us that are looking for property in the private sector it is a major headache.

Q131 Lord Morris of Handsworth: I hate quoting your evidence, but never mind. You referred in your evidence to a win-win situation as outcomes for individuals are improved, rights are upheld and savings made. Could you give us some practical examples of how enabling access to independent living can at the same time result in cost savings?

Tracy Hammond: I have a number of people in mind and I did have when I wrote that. There is a gentleman who had learning disabilities. He had been cloaking them and had ended up in prison as a result of that. He did 20 years in prison for a string of fairly minor offences. It was eventually recognised that he had a learning disability and he has been with us for eight years. KeyRing is a low support service. We support around nine people in the community, depending on the locality, for around £40,000. This gentleman receives probably two hours of formal support with a lot of support to get involved in the community. He has been out of prison for eight years and is now a full-time dad to his son, which is something that he was told would never happen. This is saving the country a huge amount of money. The cost of him being in prison would pay for the support of everybody else in that network. Added to that he actually has a life, he is giving things back to the community and he has been involved in a soup kitchen for the homeless. He is so well known in the community that he is not going to reoffend because why would he tarnish the reputation he has built up?

I have another guy who, after his father sadly died, attempted to live alone independently without any support and ended up falling prey to antisocial behaviour. He was broken into 10 times over a period of three months. I could not believe that statistic so I went back and checked it twice. He then joined our services and again was supported to get involved in the community and to become well known. When we first did a relationship map with him the only people in his life were people who were paid to be there. He had no real friends; he had nobody in his intimacy circle. He has been with us for probably about 10 years now and he just held a large birthday party. There were about 30 people at that birthday party, many of whom knew him really well. The outcomes for him are very plain but in terms of outcomes for the country, the cost alone of having him at duty desk all the time, the crisis intervention, and work that needed to be done on the property after he had been broken into, was all costing money. So I see that as a win-win situation and it was that kind of example that I was talking about.

Q132 Lord Morris of Handsworth: Okay, so we fall back on the old adage that dedication might be expensive but ignorance costs a lot more.

Tracy Hammond: Absolutely. I actually have something called the CSED report, which is care services efficiency delivery. This has done a case study on us, and it is pretty evident that early intervention has been shown, quite conclusively, to save money in these cases.

Q133 Lord Morris of Handsworth: My briefing note tells me that I should be exploring the issue of housing with you, but I am sure that my colleagues on the Committee here will agree that we have traversed that question and explored it. We have talked about new build, adaptation, whether there should be mandatory standards and so on. So I will not repeat the housing issue because it is something on which we have drilled down quite a lot. However, the fact of the matter is that you can have the best house on the street in the community but if you cannot get out of it, in terms of social mobility, your life is still impeded. This takes me on to the issue of transport. Not much has been said on this so far in our inquiry and we have not heard much evidence on transport, which is an integral part of independent living and access to mobility. What would you like to say to the Committee about linking the transport needs with the housing needs to give social mobility?

Kate Sheehan: As we come from a housing section we do tend to get quite bogged down about housing but transport is also key. For example, I worked with somebody who had had a spinal injury and we were trying to find her a house that would meet her needs. What we actually had to do was work backwards; we had to find a railway station that was going to meet her needs and then look at the facility around it. That restricted where she could live because she wanted to return to work—she worked for a charity in the centre of London—and we had to look very hard at which train station could accommodate her needs and get her up to London in a reasonable timeframe and at commuter time. That was a real difficulty.

There have been huge gains in accessible taxis but, again, it is very expensive. The problem is that people with disabilities tend to be on lower incomes, so there is a real issue about whether they can afford to use them. There have been huge gains on buses as well. They are certainly better designed in the London area, but it is not always easy for everybody to get on a bus. Often, even if you are a competent wheelchair user, you still need assistance to do it and you need to plan it. There is also an attitudinal aspect. If you are with a friend who has a disability and you get on a bus you are slower; it takes time to get on. So we need a form of education for the general public that this is somebody who just needs a bit of extra time, just like a toddler or an older person with a walking stick may need time. There is a huge element of occupation around there.

Can I just say one other thing that I am desperate to get in? I know you do not really want to talk about housing any more but this is one of the key things for me. We have talked about the public sector but I do think the private and commercial sector really should have a role in this as well. Yes there should be statutory provision but things like equipment and adaptation for people with disabilities are phenomenally expensive.

Lord Morris of Handsworth: You have informed us on that. You made it very clear that it was not just the public sector; it was the private sector as well. That point, trust me, is well registered.

The Chairman: Baroness Campbell, you wished to ask a question to Breakthrough?

Q134 Baroness Campbell of Surbiton: Yes I do. It will be no surprise to you Lorraine that we have had a lot of stress on the involvement of disabled people in the evidence that we have received. I was quite interested to find that, in your written evidence, you emphasise that “reducing bureaucracy should not be done at the expense of measures that allow disabled people to be meaningfully involved in decision making.” First of all, please explain to us what you mean by that and your concerns on this issue.

Lorraine Gradwell: My concerns were around the fact that disabled people as a group have a whole different range of communication needs. If involvement is going to happen, with

consultation and co-production, then those information and access needs need to be met. Unfortunately, that probably requires a level of bureaucracy in order to make it happen.

Q135 Baroness Campbell of Surbiton: You obviously sense that there is a danger here. Do you want to tell us what you think the dangers are?

Lorraine Gradwell: I think the danger is that “the devil take the hindmost”, if I can use that expression. Involvement in policy making and consultation with groups that might have communication impairments or might find it difficult to get involved for a whole range of reasons raises a number of issues. It costs more to involve people, it takes longer and it requires better advanced planning. The danger, which we have seen in some consultations, is that people say they have to get through something quickly and do not have time to do this. They say that if they can have a response by a week on Friday then they may take it on board. As an organisation, we have often had to weigh up whether we should put aside what we are doing and respond to an urgent request for involvement or whether we should say that actually there is not time to do that meaningfully. Meaningful involvement is the key there.

I know I have said that it costs more, and it does cost more because you might need to put things into Braille, you might need sign language interpreters and these things do cost. However, if it is planned in and it is a universally accepted issue, then that cost will be minimised and spread.

Q136 Baroness Campbell of Surbiton: Is there any recent Government policy that makes you think this is not taken into account? Obviously, involvement has been something that all Governments say they want to do. Is there anything that worries you at the moment?

Lorraine Gradwell: The Equality Act removed the requirement on local authorities to involve, for instance. Why do that if it is committed to involving people? I think that is the biggest example that gives people rise for concern.

Q137 Baroness Campbell of Surbiton: What would that do? How is that playing out?

Lorraine Gradwell: Local disabled people who are trying to influence what is happening in the locality and trying to be a part of the Big Society and so on, previously had a way of taking local statutory bodies to task if they were not doing proper consultation. That has been removed.

Q138 Baroness Campbell of Surbiton: Okay, so what more could be done to involved disabled people in policy making from now on?

Lorraine Gradwell: First of all replace that requirement. There are important lessons being learned about co-production in the right to control initiative and they could be spread across Government. The idea is of stopping working in silos and the lessons could go across to the Treasury and to Communities and Local Government. I think it is a shame that the Equalities Office does not really have a responsibility for disability, which sits within DWP, and I think a joint responsibility would send a strong message to disabled people. There does need to be consideration, if the Government is going ahead with its Big Society plans, that disabled people need to be involved at a local level and at a regional level. The danger is that that just will not happen.

Baroness Campbell of Surbiton: Okay, thanks.

Q139 Rehman Chishti: Some of this has already been covered but I would like to ask it quickly. What lessons have you learnt, as a service provider, about how to enable real

involvement in decision making by people with learning disabilities and others whose voices are less likely to be heard? Secondly, what implications are there for Government if it is to fulfil its obligations under the CRPD to involve disabled people?

Tracy Hammond: Firstly, sometimes the involvement we see at the moment with calls for information can feel a little bit tokenistic. I worked through the Transparency in Outcomes document with some service users at our national forum a while ago and I have to say that actually the easy read was so simplistic that it did not really get to the nub of the issues being discussed in the Transparency in Outcomes document. The first thing to do is to recognise that there are levels of involvement. Certainly our service users who have a learning disability would have been well able to answer questions in more depth. In fact I actually took them through the whole of the standard document.

One of the problems that we have is that organisations across the country are being squeezed in terms of money, which actually means in terms of staff time as well. So we need to be able to do things well and properly by having good resources. For me it would be fantastic if somebody else had put together some PowerPoint slides to introduce the topics that are being covered so I could just beam them up on the board and then start to talk to people. So I think a real good range of resources is one of the things.

National Government is not too bad about timing, but with local authorities very often things are sent out that I cannot turn around with people who have low support needs. One of the issues with people who have low support needs is that, because they have low support needs, we only see them once or twice a week. Very often we get people together but we will only do that on a monthly basis or a fortnightly basis. That means that in order to plan good consultation in we need loads of warning and good resources. If we are asked to turn something around in two weeks it becomes very difficult. Certainly at a local level that has happened to us, although it had not happened at a national level.

So it is about recognising that not everybody has the same requirements and there are a whole raft of levels that people can get involved in and then trying to resource those levels as best you can, so that service providers like ourselves can give you the quick turnaround that you need.

The Chairman: Well thank you very much for the comprehensive and thorough way in which you have answered our questions. If you feel that we have not covered everything we would be very happy to hear from you again. Thank you very much. Could the other witnesses now come forward please?

Examination of Witnesses

Tracey Jannaway, Independent Living Alternatives, **Hazel Roper**, Independent Living Association, **Nadra Ahmed**, National Care Association and **Adam Penwarden**, Turning Point, gave evidence.

Q140 The Chairman: Good afternoon and welcome to the Joint Committee on Human Rights. For the record, can you all introduce yourselves please?

Adam Penwarden: My name is Adam Penwarden. I am the Director of Learning Disability Services for Turning Point.

Hazel Roper: I am Hazel Roper. I am the Quality and Customer Engagement Manager for the Independent Living Association.

Tracey Jannaway: I am Tracey Jannaway and I am the Director of Independent Living Alternatives.

Nadra Ahmed: I am Nadra Ahmed. I am the Chairman of the National Care Association.

Q141 The Chairman: Thank you very much. I begin by asking a question of Mr Penwarden in relation to Turning Point. I would like to refer you to your website where you talk about your ethos for the last 40 years that “the individual is in the driving seat”. You also say that “the changes happening now mean individuals, their families and carers can have more control than ever over their support”. Can you explain this approach a little further and what implications this approach has for you as a service provider?

Adam Penwarden: Yes, certainly. My main perspective will be from the point of view of people with a learning disability. There are three main strands that I would draw out from that. The first one is legislative and colleagues earlier gave a very good and clear account of the progress in terms of legislation that we have made.

The second strand is around good practice. I have worked with people with learning disabilities for about 20 years and what I have seen is a collective effort of organisations, service providers, the people we support and families in terms of driving forward what is good practice with independent living—what it looks like, what it feels like and what are good examples of it. While most organisations will have their own particular methodology, the general thrust towards keeping people at the centre of things—what are called person-centred approaches—is pretty universal and there is general agreement that that is the way to work. The detail of it varies and, I have to be honest, the quality of it varies too. There is no point in pretending that it is all perfect but there is a general thrust towards that, which I think has been very helpful.

The third point is about personalisation and the move towards personal budgets. I think there is more work to be done on that. I think that personal budgets are working brilliantly for some people and much less well for others. It is worth noting that the Government have ever so slightly moved the goalposts in terms of what constitutes a personal budget. It is now just a personal allocation. So while there seem to be very large numbers of people with personal budgets, relatively few of those people actually have direct control of that money. Nonetheless, it has had a huge impact. One of the consequences of this has been organisations like my own. We know full well that every single person we support could choose to go and be supported by somebody else. If they are not happy, or their family is not happy, with what we are doing, they can say that they do not want Turning Point and will go to Mencap or Dimensions or whoever. That is a real drive for us to make sure that we are supplying a service to people that they actually need and want. Those would be my three points.

The Chairman: Thank you very much.

Q142 Lord Morris of Handsworth: My question is to Independent Living Alternatives. Your organisation states, “As disabled people we must be in control of our services, not controlled by the services that are available”. What does this mean in practice and what contribution does a service such as yours aim to make towards this aspiration?

Tracey Jannaway: Historically, disabled people have received services that have been prescribed for them. ILA very much comes from the perspective that we will go to people and determine what those services are and what people want to have. It is not about saying, “You are going to get up at 10 o’clock in the morning” or, “You are going to get up”. You actually do not have to get up. It is a life choice whether you get up or do not get up. It is a life choice whether you have a bath or do not have a bath. It is coming very much from the perspective of saying, “What do you, as an end user, want?” For us as an organisation, that means meeting with each individual who uses our service or wants to employ their own PAs directly, or whatever service they want to use, and starting from the point of: what do you want?

Q143 Lord Morris of Handsworth: What are the constraints on delivering the “what do you want?”

Tracey Jannaway: Obviously the normal constraints that there are on everybody. We cannot perform miracles. There are limits in terms of budget and finance available. There are limits in terms of housing that is available. If somebody wants to live independently and has not got a house and cannot get a house to live in because we have a lack of decent accessible housing stock, then we have a problem. At the moment we also have a problem in that the country is cash strapped and people are now divided up into whether their needs are moderate, critical or substantial. It tends to be people with critical needs that are receiving services. Those with substantial needs in the majority of areas are getting services, although they are slowly being cut back. But if you just need a little bit of housework doing, you will not get that funded. That is a huge constraint. I meet people who do not get that tiny bit of help. They then go into a downward decline and then need a massive amount of help to sort them out. In my opinion that is illogical.

Q144 Baroness Campbell of Surbiton: My question is to ILA West Sussex. You describe yourselves as “a user-led organisation”. Lots of people describe themselves as that these days. Can you explain what that really means in practice and what difference it makes to the way you think or to the way you work with service users?

Hazel Roper: Our charity constitution says that we must have at least 51% of our trustees being either disabled people or their unpaid carers. So that is the foundation stone and everything comes from that. That means that our governing board makes decisions on how the organisation is run and there is a direct contribution from disabled people and carers. That runs through the organisation affecting our ethos, because those trustees decide where money is distributed within the organisation, the priorities that we have and our aims and objectives. It ensures that we operate the social model of disability throughout the Independent Living Association. That means that we see society as a barrier to access and opportunities that are available to disabled people rather than viewing disability as being about a medical condition that an individual has, which would be the medical model. Our objectives within that are that we help people with care needs to be independent and that we develop our services to help people gain and maintain that independence. We would use the fact that we are a ULO, a user-led organisation, to make sure that we invest our surpluses to improve and widen our services based on what people are telling us they want.

Q145 Baroness Campbell of Surbiton: Okay, that is good. Thank you.

Baroness Campbell of Surbiton: Nadra Ahmed, I have not seen you for many years, hello.

Nadra Ahmed: I know, I am still around.

Lord Morris of Handsworth: A reunion.

Q146 Baroness Campbell of Surbiton: It is good to see you anyway. So Nadra, what does independent living mean to the care providers that you represent?

Nadra Ahmed: I think it is important to say that one of the main outcomes for residential care providers has always been about promotion around independence. These are terminologies that get used but it is becoming much more in the framework of the work that we do. It is an interesting notion because when people come into residential care, especially now as opposed to 20 years ago, they have been assessed as needing quite substantial support and care in order to continue to live a meaningful life. Independence is one of them.

Looking at personalisation, we promote independence just as my colleagues here do. It is said that when people go into residential care we make them dependent. Actually we do not make them dependent; we try to make them as independent as we can by providing support where they did not have it before. If they had had it before, they would still be in the setting that they come to us from. So for as long as possible we try to keep people independent. Contrary to popular belief, making people dependent makes it much harder for us to look after them. If you make somebody dependent on something simple such as feeding it means that you need two carers around all the time to make sure that the person is fed. So all the time they can remain independent we try to do that.

We also find that a lot of providers now are looking at the accommodation to make sure they promote independence through people's ability to come in and out of the services. Providers are also trying very hard to make sure that there are therapists around. There is a shift towards making sure that residential care does not become seen as a dependency-led service.

Q147 Baroness Campbell of Surbiton: You have talked a lot about physiotherapists and enabling people to feed themselves and so on, but you all know that Article 19 obligations extend far beyond those. It is about full participation or as much participation in the community as possible. How can your providers really go for that Article 19 obligation?

Nadra Ahmed: Providers are doing that. We are opening up our homes as communities because the legislation has now allowed us to become much more open and allow communities in and people to go out into communities without stigma. That used to be an issue.

Q148 Baroness Campbell of Surbiton: How are you doing that though? Can you give me some practical examples?

Nadra Ahmed: Well, for example, we have a service in Norfolk where they have used money that came out of Sky connectivity where internet is put in so service users can use it. They have actually started an internet café within the service. So not only are the people who are within the home able to use it but there are also classes being made available for people outside of the service to come in. So there is equality there.

Just recently I opened a care home where they have a café and a newsagent within the service, which service users are helping to run. This is in a service for older people, some with mental health issues and some with early onset dementia. So the move is happening. It

is not the ideal world yet but we are moving towards that. There is innovation out there and providers are always looking for that innovation because that is what the sector does best.

Baroness Campbell of Surbiton: Okay, thanks.

Q149 Rehman Chishti: I have a question that is in three different parts and for three different people. Firstly it is to ILA West Sussex, Independent Living Alternatives and Turning Point. Can you briefly outline what contribution you think the current policies on adult social care, and the way they are being implemented by local authorities, make towards delivering independent living for disabled people? Secondly, how are these policies and their implementation impacting on the services you provide? Thirdly, are there specific features of the commissioning process that help to promote or create barriers to your ability to deliver independent living for your service users, and are there any improvements you would like to see? So if you want to touch upon each one and if there is any cross over then feel free to say.

Adam Penwarden: Shall I?

Q150 Rehman Chishti: Hazel, come on.

Hazel Roper: Okay. Some of the things we are hearing from our disabled members we have consulted is that they feel that the cuts are a kneejerk reaction deliberately to target disabled people. That is how it comes across to them. In fact they have reported an increase in hate crime, public abuse on the street, and they find that government policy, in the way it is being represented through the media, is actually portraying disabled people as scroungers or people who do not deserve the support that is coming across from the state. So there is an important message there for politicians in the messages that need to come across about what disabled people need and the funding of independent living.

From the cuts consultation, the things we are hearing from our members is that they feel pre-decided. The questions that are in consultation are coming across as leading questions and there is little option for them to give responses outside of those options. Through that process, with minimal options in a consultation, they feel bullied into the acceptance of what they feel is inevitable anyway.

From the way national government is promoting personalisation, disabled people have come to believe that will lead to greater flexibility. Luckily, through direct payments and other initiatives, they have actually seen that. What it looks like at the moment is that government policies are pushing personalisation backwards and it is actually becoming retrograde. So things like assessments are not being made holistically but are only looking at personal care and tossing aside things like domestic, social and community access needs as if there is no funding for that so there should not even be a discussion around it. An interesting case I heard was where a locum social worker was working with a disabled person and they found that the locum was a lot more responsive to their needs because that professional was not under the same pressure as the regular team, hearing the same message from their budget holder. So that is a threat to personalisation.

Aside from what we view as social care, there are other government departments that are affecting the way disabled people access independent living. We are hearing from disabled members that they are concerned about the HMRC in their plans to cut down on the advice and forms, and the mechanisms for accessing that. So that in the future it will be online access only, so people will not be able to phone up or get that information face to face and they will not be able to get it in a paper format. That is an issue because an individual disabled employer who is perhaps pursuing independent living through direct payments might not have access to a computer; they might not be able to afford a computer; they might not be able to understand how to work a computer; or they might not be physically

able to operate a computer. Yet we are hearing from members that there is not alternative access from HMRC.

Finally, on a local level, we have had concern from our members on the closure of public disabled toilets. They believe that the council is saying they are closing because of the cost of maintaining them. Are we saying that it is okay for disabled people to be trapped at home and not able to access the high street and local community facilities because the toilets have to close?

Adam Penwarden: The impact of the implementation of the government policies for us is that we are doing more for less. That is just a fact. In all the areas we are working in we have had reductions in our income and we sit down and negotiate on those things. That is the direct impact. Up to a point that has been manageable, but not for everybody and not in every instance. My worry is for 2012-2013 and 2013-2014 because we just do not know what kind of impact the Comprehensive Spending Review is going to have in those next two years. I have no way of planning beyond the end of 31 March 2012, which is scary. We were invited to a consultation meeting in Hertfordshire a couple of weeks ago, at which there was a general view from large and small organisations that just having the chance to plan ahead two or three years, even if it does mean less money, would be better than the current circumstances of simply not being able to plan. So that is one impact.

In terms of commissioning, I would come back to what earlier colleagues were saying about the fair access to care system, which really is a nightmare. The evidence is beginning to come through about groups of people who do not get to a substantial level and whose services are disappearing. The consequential impact of that is a tough one and there will be difficulties with the ability of organisations like mine to support people at a relatively modest level. If you are a local authority FD in the social care department you are making tough decisions. I have every sympathy for them and I understand; I am not making a political point here. They have to make some difficult decisions. If the impact of you not supporting an individual means they will end up in the criminal justice system that is a very bad thing but ultimately it is not your problem. If they are in the criminal justice system it is not the responsibility of the local authority. I am not suggesting that is a cynical approach at all; I am just saying that that is the reality of the situation.

The other aspect in terms of self-advocacy is that there has been a real impact on self-advocacy groups. A Learning Disability Commission report last year identified that 80% of self advocacy groups were really, really struggling and that 23 out of 120 had already gone out of business. Again, if you are making tough decisions at a local authority level you do not have a legal obligation to do that. But you do have a legal obligation to make sure that children are protected, that adults are protected and so on. So there are consequences to this that we are not seeing yet and I think that is a real problem.

On the positive side I would reiterate my point about personal budgets and personalisation. I do think that has had a significant impact on people's ability to control their own destiny and do all the things that colleagues have described. Again, I would highlight the point that a lot of things that are recorded as personal budgets are not actually personal budgets and that could potentially be a problem.

There is one very practical point at the moment—I do not know whether the Committee is aware of it—which is the decision by a housing benefit tribunal known as the Wychavon decision. A housing benefit judge has said that if you lack the capacity to sign a tenancy, as the substantial majority of the people we support do, you have no entitlement to housing benefit unless you have the Court of Protection deputyship. We are a bit shocked by this. We think it needs looking at and we have asked, through the Voluntary Organisations Disability Group, for the Minister, Paul Burstow, to have a look at this. If that were to

succeed there would need to be a change in the law to make sure that people who do not have the capacity to sign a tenancy agreement can obtain housing benefit.

If that were to succeed, it is going to need a change in the law to make sure that people who do not have the capacity to sign a tenancy agreement can obtain housing benefit.

Q151 Rehman Chishti: Anybody else?

Nadra Ahmed: Around commissioning, for the residential care sector that I represent, it is certainly one of the biggest challenges providers currently have, because there is no consultation about the commissioning of services. We are at a point where the only message you get from commissioners is that they are looking for efficiencies in the payment but they obviously want the services to be of the highest quality. That is a real challenge for providers because we are not untouched by all the other things that everybody else is touched by in rising prices and we have workforce issues. So there is a greater expectation. There is no meaningful dialogue with commissioners. We travel up and down the country regularly. In the first six months of the year we meet thousands of providers—that is part of the role that we have—and wherever we go there is a real call out because on the one side they have the Care Quality Commission expressing, rightly so, that it wants a quality service and then they have the commissioners saying, “But you must deliver this for less money”. That creates a real imbalance, because the deliverability becomes really difficult.

Q152 Rehman Chishti: Can I come back on one thing before we move on? We have talked about the pressure, the resources and the quality of care: of course; it is absolutely right people should get that quality of care. But the point that I want clarification on is this. Knowing that there are few resources at the moment throughout every sector in every part of the country, could there not be more scope for collaborative working between local authorities to ensure that those services are there? At the moment you have local authorities sometimes not working collaboratively, but if they are, I think a lot of these issues can be dealt with. I used to sit on a local authority at cabinet level, so I know where you need local authorities working together. Where there are fewer resources, is there scope for collaborative working and working together in a different way to overcome that?

Nadra Ahmed: I think the short answer is probably yes, there is. Unfortunately, whenever this has happened and local authorities have worked collaboratively, they have worked together to drive prices down. That is how it works, unfortunately. It is not a positive collaboration; it is about how we can do it better this way. That is a real tricky one for us. But collaborative work with providers—it would be fantastic if we could all sit round a table. There have been pockets of good practice. Certainly in the area that I live in money was given to the DH and through the DH for training; the money was given to an organisation to deliver it. So that was working in private partnership. I think there is room for collaborative work. Unfortunately, because of what you have just indicated about the drivers of the downward push, it is quite often not for the benefit of service users.

Q153 Rehman Chishti: But it can be if you have got a local authority that is not so great and you have got another department in another area nearby that is. Then you have got the positive sides of that, not simply in resources but in terms of quality.

Nadra Ahmed: Yes, I think you are absolutely right; there is.

Tracey Jannaway: Commissioning for services, from our point of view, creates a conflict with the whole concept of independent living because you tend to end up having a block service and, again, you are saying to people, “This is the service that is available”; you are not saying, “What service do you want?”

Q154 Lord Morris of Handsworth: My question is to the National Care Association. As you are aware, Article 19 of the UN Convention gives disabled people the right to choose where and with whom they live and to have the same choice and control over their lives as non-disabled people. The Government have told us that policies such as rolling out personal budgets will promote these rights. What implication do these rights and such policies as personal budgets have for the providers that you represent?

Nadra Ahmed: We welcome the right of people to make decisions about their own lives. I think that is how anyone would want to operate. If personal budgets could be used in making residential care a positive choice, that would also be good. I started working in social care in my first home in 1981. There were no restrictions; people used to walk into my care home and say that was where they wanted to be, because they made that positive choice. Things have changed somewhat, because we are now told people do not make a positive choice towards coming into residential care, which I still struggle with sometimes. At the moment, we are in a situation where people cannot use those budgets to come into residential care if they so wished. The National Care Association represents a plethora of organisations, including learning disabilities and domiciliary care. We believe that in this very diverse and complex world individuals are able to choose.

Q155 Lord Morris of Handsworth: Can I stop you there? If the budget is personal, what are the constraints on choice of use?

Nadra Ahmed: I cannot answer that fully. All I know is that the personal budget cannot be used to go into residential care at the current time.

Q156 Lord Morris of Handsworth: But you do not know why?

Nadra Ahmed: I do not know why; that is part of the legislation.

Q157 Baroness Campbell of Surbiton: Can I just ask you one more question about control? I think we are missing one of the biggest things that disabled people tell us. They say that once they go into a residential home they feel they lose control. How can your care providers extend control in their homes? For instance, how many of the care providers run management committees where the users have a say in how the home is run? Can you give me a feel for structured control rather than just, “We give them control”? It has got to be structured.

Nadra Ahmed: I would love to say that every provider does it but I am sure you would disbelieve me in that. But we know that there are providers who do have what they call residents committees and they talk to them about everything they do. I certainly did when I had a service. I know of providers who are involving the service users when they interview for staff, because it is part of the employment process that a service user is given the opportunity to look at the candidates. I have always had this concern around using the word ‘control’, because when you give control to somebody, you take it away from somebody else. I think it is about being able to make your own choices and make decisions around your own living. One of the biggest things that we have in residential care is that when somebody comes into a service, we must have a very robust care plan because of personalisation. We have been doing that since the 1980s. It is nothing new to us. Some people do it really well; some people do not do it very well. But that is certainly the drive that the National Care Association has always had; people should be in control of the service that they provide. Sometimes we are restricted because we are told by regulators, “You cannot allow a person to do this”, because of the health and safety issues or the risk assessment. I had a case where I was told that I had to lock down my windows on the second floor to open only so

much because the risk was that the person would jump out the window. The person was mortified that they could no longer open their window.

Q158 Baroness Campbell of Surbiton: I accept that. I am more interested in the people in the home deciding how they live together and that kind of control and then offering that to the management committee and saying, “This is how we would like our home to be run”. Does that happen?

Nadra Ahmed: I think it is happening much more now than it ever was.

Q159 Baroness Campbell of Surbiton: You don’t happen to have any statistical evidence or anything that we can look at?

Nadra Ahmed: We had providers recently on one of the road shows saying to us that they had really wanted to open up the care home to meals on wheels—a lunchtime club—and they went to the residents of the care home, who said that they did not want strangers coming into their service.

Q160 Baroness Campbell of Surbiton: Maybe they just didn’t want the meals on wheels.

Nadra Ahmed: I didn’t mean meals on wheels; I meant a luncheon club. But they then decided they would do meals on wheels. That is why I got confused. They wanted to have a luncheon club and they wanted to do that because they had the capacity and the facility, but they had a very strong message from their residents that they did not want other people coming into the service.

Q161 Baroness Campbell of Surbiton: You have told us quite a lot about commissioning and the cost of that. Commissioning is key to independent living. Are there any other improvements that you would like to see in the commissioning process?

Nadra Ahmed: Any improvements?

Baroness Campbell of Surbiton: Yes. To promote Article 19.

Nadra Ahmed: I would like to see much more involvement about the choice imperative, for sure, because I am not sure that when commissioners come to talk to us about commissioning they are looking at the bigger picture around choice. There is a massive misunderstanding around what choice means, because commissioners, when they commission services, are going for a particular type of service. They are not always looking at what the individual’s needs and rights are.

Q162 Baroness Campbell of Surbiton: Do you think they are aware of Article 19?

Nadra Ahmed: The commissioners?

Baroness Campbell of Surbiton: Yes. In your opinion.

Nadra Ahmed: In my opinion, it is very patchy.

Hazel Roper: On the commissioning point, I think that if we want to meet the objectives of Article 19, then we need to allow ULOs to be on an equal playing field in that commissioning process. I think the way that we do that is recognise that ULOs are typically small organisations without huge teams of staff sitting there ready to do huge great commissioning tenders. For example, things like massive, multiple stage tendering processes will disadvantage small to medium organisations such as ULOs. Things like the fact that ULOs in the past have typically relied upon a grants process and we are all relatively green to the tendering process mean that we are a step behind. So things like local authorities offering training to small charities and ULOs on what the tendering process means helps the commissioning process open up. I think that local authorities can be clearer on what they

mean by quality. For example, our organisation, the Independent Living Association, has had the experience that in one tender a voluntary sector quality standard such as PQASSO is considered acceptable; in another tender, the quality standard ISO9001 has been the only considered acceptable standard. That is quite broad for a small organisation to cope with. I also think that everything that is built into a tendering process needs to be adding value. So, for example, small organisations may struggle to provide a track record of three years' audited accounts. It needs to be considered whether that is essential to the kind of service that is being tendered for. I think there is an opportunity for tenderers to ask ULOs what sorts of things should be built into their tendering process and, hopefully, level that playing field.

Q163 Lord Morris of Handsworth: You will all be pleased to know that this is my last question, so I have decided to share it between two of you. It is to the Independent Living Association West Sussex branch and Independent Living Alternatives. What contribution is the Independent Living Fund currently making to help your service users access independent living? Are there any key features of the fund that you think need to be continued in order that the Government can deliver their obligation under Article 19?

Tracey Jannaway: The majority of people who use ILA are receiving some level of funding from the Independent Living Fund and people are very scared as to what is now going to happen and where it is going to go. There has not been a concrete response as to what funding people will get in the future. People are scared generally every time there is a review that they are going to lose some kind of service. As a result of that, my experience is that people also learn how to play the game and learn how to continue to get their funding, which wastes an incredible amount of money with people coming out and reviewing people, reviewing people and reviewing people. If someone has a disability that means that their needs are not going to change, why does someone have to come out every year and say, "Can you do this? Can you do that?" I would also pick up on the almost trick questioning that is used in terms of asking someone, "Do you have any problems with your mobility?" I had it recently where a woman who uses a wheelchair and has no physical movement said, "No, I have no problems with my mobility because I have my wheelchair." But that was not the answer the social worker needed in order for her to increase her funding, which was what was needed. So it is a game. We spend a lot of time playing a game. Going back to the ILF, what scares people the most is that that money is going to end up going into the social services pot and just being lost.

Hazel Roper: That is definitely the key message from the Independent Living Association members. There is no doubt that that money is needed. There are, interestingly, differing views on whether people prefer for the ILF to have continued and be a discrete pot of money which then came with all this baggage of separate reassessments and sometimes not very flexible rules around the use of ILF. Some people still prefer for ILF to be a discrete pot of money because they feel that, the minute it is absorbed into the general social services pot of money, it will cease to be available for severely disabled people who have those additional needs. The other thing we are hearing is that with the reassessment process, yes, generally people are finding that very stressful. However, we have also heard that having a second pair of eyes coming in and reassessing means that someone looks at the holistic needs from a perspective that is different from their social worker. So interestingly, when we consulted on all of the issues that came up today, the one that was the most differing was the ILF. There was not a true consensus about whether it should continue to be a nationally managed pot of money or a locally organised pot of money. But definitely ring fenced, was the message.

Q164 The Chairman: Could we now move on to Disability Living Allowance and people living in residential care? Baroness Stowell.

Baroness Stowell of Beeston: Hi, I am Tina Stowell. My questions are to Nadra, representing the National Care Association. I have two questions. I will ask the questions first and then I will explain the context in which I am asking the questions, because I think that is an easier way of doing this. What do you think would be the impact of removing eligibility for the mobility component of the Disability Living Allowance from people living in residential homes? What experience do your members have of any overlap of provision? The reason why I am asking this is because, as I understand it, the Government are intending to reform the DLA to remove overlaps in provision of transport and mobility between service providers and local authorities. This is their way of trying to reduce costs but ensuring that the service is still provided to meet the needs of people who are living in residential homes.

Nadra Ahmed: Interestingly, I have two perspectives on this—one as the Chair of the National Care Association and the membership, and one as a trustee of Parkinson's UK. I will try to focus on the residential one to start with, if I may. I think the allowance is something that promotes independence within residential settings. People who have it have more flexibility to be able to get out and about by using the transport systems. It allows blue badges and all of that. So I think it will certainly have an impact if that goes away. Providers are thinking about this. It is one of those things that does not touch the provider because it is individual. You come in with it and it is part of your own personal budget to do with as you please, but we are able to support people to use it properly. So it is one of those subjects that the provider sector has not really got that involved in. I have a mother with Parkinson's in a care home and I know that this is an important part of her living. There is concern around the reassessment of this and how that will all come back—very similar concerns raised earlier—because the process is asking for 20% cuts. The reassessment process is going to cost a fortune but it is going to be looking at 20% efficiencies. One of the worries is that when the reassessment process happens and people are assessed on a good day, especially people who have Parkinson's who can have a really good day, they will not be seen as severe and it will be only people with a severe condition who will get it. So there is a lot of uncertainty; a lot of what was reflected by my colleagues earlier around the reassessment process. I think that is there. There is concern around it.

Q165 Baroness Stowell of Beeston: It sounds to me that what you are saying is there is not much overlap between service providers providing mobility and local authorities.

Nadra Ahmed: A lot of service providers do have quite a lot of equipment—they have disabled minibuses in the service for the use of everybody. There was one gentleman who was saying that if that goes for his partner, who is in a service, that might mean that he will not be able to take her away on holiday.

The Chairman: Can I pause at this point? We are inquorate at the moment. Mr Chishti has slipped out and we are trying to rescue him. None of this evidence can be considered valid until he comes back in.

[The Committee suspended for two minutes while it was inquorate.]

The Chairman: I cannot remember who was speaking.

Baroness Stowell of Beeston: Adam was about to tell us something.

The Chairman: Mr Penwarden.

Adam Penwarden: I take your point that the Government's argument is that there has been dual funding. The reality is that most of the contracts that I am responsible for specifically

exclude from the cost of contract the cost of transport. Therefore, if the £43 a week is lost by those individuals, it will not be replaced. The point about minibuses is all very well and good but there is no income for those minibuses other than the income that people receive through the DLA mobility allowance. You can argue about whether it is a much needed reform or not but I do not believe that it was ever the Government's intention to take money away from probably the most severely disabled group of people. If you have got higher rate DLA mobility and you live in a registered care home, you really are probably pretty disabled. It does feel as if that was not quite what the Government were getting at. I know through the LDC and the Voluntary Organisations Disability Group that there have been a lot of conversations with Maria Miller trying to find a way through this and we continue so to do. The bottom line is, whatever the rights and wrongs in the past, if those folk lose that £43 a week, it is not being found from anywhere else at the moment.

Q166 Baroness Stowell of Beeston: Moving on now to the general topic of whether independent living is all about money in terms of making sure that people are able to exercise their rights to independent living in a way that is not just focusing on funding, my question is directed to the National Care Association. It is quite a sensitive question, because what we have heard from some residential care services is that they have low expectations about the level of choice and what kind of life their service users can have. Some people have told us that it is service providers' attitudes and the way resources are used that are more important than the level of resources available. I wondered if that was something you would agree with. What impact has the application of the Human Rights Act—as in our own national Human Rights Act—to residential care had on your members?

Nadra Ahmed: I am not absolutely clear about the question but I will start and then if I am not going down the right path you will correct me. Human rights can be breached only by a public body. That is the statement we have been given. So I suppose that for care home providers Article 19 would not be chapter and verse in their hearts and minds. But I think that the rights of individuals certainly are. To me, that is the human right of an individual to live the best life that they can within a setting. I am not sure whether you are saying that the resources, which are the fees that they receive, are not properly used. Is that what you are saying?

Q167 Baroness Stowell of Beeston: No. Forgive me; I was not expressing myself as clearly as I need to for something as sensitive as this. The point I am trying to get at is that independent living requires proper resourcing and funding and we have talked about the very important aspects of that. But it goes beyond that in terms of it is about attitude and it is about the way in which people feel—it is the sort of things we were talking about when you first sat down, really. It is really how much importance the people who are responsible for providing services—and I am talking about residential care—place on ensuring that the people who are living in their homes are able to live as independently as they can, regardless of the resourcing, and in line with what is now their right under the United Nations Convention and also within the terms of the Human Rights Act.

Nadra Ahmed: I have to say that every responsible provider who has opened a service has opened it to serve the vulnerable people that they look after. I stand by that because I visit many services and I talk to a lot of people. I think there is poor practice out there and I honestly do not think that that is the provider sector's issue. I think that is the issue of the regulator. They need to go out and sort that out. I want to put that aside. Every responsible provider works on the basis that the people that they are caring for are there as independent individuals. They come in with their aspirations and very often with the aspiration of the family as well. We used to argue this years ago: who do you have an en

suite room for? Do you have it for the individual who never uses it because they may be doubly incontinent, or do you have it for the family because that is what they think that they want? We used to have these debates. I believe that providers go in to look after somebody with the ethos that it is for the individual. But we also have to create a community within that, because they cannot operate in silos. So independent living within a service is that person's personal care plan and the staff are responsible. We make sure that there are individuals who have their individual needs in mind and they work to that care plan. Of course, those residents within our services who can respond tell us what they want. Very often, families tell us what they want. So they will live as independent a life as possible. Resources is a whole different subject, because if somebody wants to go to the seaside every day and they live in the middle of the country, we may not be able to do that for them. But we will try to meet their needs, because they know when they come in what their likes and dislikes are. If I use my mother as an example from an ethnic minority, it is a massive challenge for the care home. My mother used to pray five times a day. They are doing their very best at this moment in time to make sure that she has her Muslim ethnic background respected—not eating pork and all of that kind of stuff. But she is not feeding anything back to them; it is us who are feeding it back to them. So her independent life is based around what we tell them. But there are people in our learning disabilities services that we represent who can tell you what they want. That is what the providers are trying to do. What worries me is when neither the service user nor the provider is involved in an assessment, especially in learning disabilities services, and people are being moved into less supported services. That I think is a real problem.

Baroness Stowell of Beeston: Thank you and I am sorry that the question was not very clear.

Q168 Baroness Campbell of Surbiton: Sorry to interject. It is just for clarification. All providers of social care that is publically funded are performing a public function and it is subject to the Human Rights Act 1998. Does the NCA give guidance to its members or does it think that the Government should give better guidance? Because if you do not even know, it worries me.

Nadra Ahmed: We do give guidance, but we were asked to interject in an appeal that was held a couple of years ago. You are absolutely right, Baroness Campbell; it is the public body that places somebody—the human rights are their responsibility. That is what we were told. But, that said, we have always upheld the Human Rights Act as part of the ethos.

Q169 Baroness Campbell of Surbiton: But do you give actual guidance?

Nadra Ahmed: We did a couple of years ago but it may be something that we need to do again.

Q170 The Chairman: Baroness Campbell, your last question.

Baroness Campbell of Surbiton: Oh yes, I am asking the very last question. 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 that independent living is not just about the money. Stop smiling. Do you agree with the Government's assessment that meeting the obligations under the UN Convention is not just about the money? Have you any concrete—and I mean concrete—examples to illustrate your answers?

Adam Penwarden: Obviously it is not just about the money. If you reflect on what happened at Winterbourne View, that was not about the money; those folk were costing the state £3,500 a week each and somebody slipped up there on their human rights. So clearly it

is not about the money. What I think it is about is the way in which providers such as ourselves work with the people we support. As I said right at the beginning, in independent living and supported living there is a generally accepted set of standards. Again I am speaking from the perspective of somebody who works with people with learning disabilities. There is a problem at the moment; the Valuing People Now programme has ground to a halt. It is interesting that it is the providers that are picking up the strands of that with the Think Local, Act Personal group. We are very happy to be involved in that and many other organisations are as well. It is interesting that it is the providers who are picking up the standard and saying, “This is what works and what doesn’t work”. So it is clearly not just about the money. I do think the risks around fair access to care services need to be tackled and I do think that one of the things that did not get much publicity when Andrew Dilnot spoke yesterday was one of his key messages, that FACS does not work and you have got to find a long-term solution to this. So my take on this is there is lots of good practice out there. Talking about working with families, one of the things that is absolutely essential is that providers can demonstrate how they work with families, particularly for people with significant communications difficulties, because that is another way of ensuring people’s human rights. Their involvement in their family and their family life is really crucial. A lot of family members have perhaps spent 20 or 30 years trying to get a decent service for their son, daughter, brother or sister. It is vital that organisations like my own and many others hear that voice. That is a really key part of it. But I do think that grasping the nettle of that long-term issue of the funding is imperative. So it is not just about the money but it is quite a bit about the money. And I think Dilnot is offering a way forward on that.

Q171 Baroness Campbell of Surbiton: That is interesting. Hazel? Tracey?

Tracey Jannaway: I do not think it is just about the money. Independent living is about, fundamentally, looking at what people want and where people want to be and believing that people can make those decisions and that there are options that are often cheaper if people are willing to take the risks. I think there is a lot of risk aversion within the whole field of independent living and people living in their own homes in the community. These are barriers which are put in the way, and often cost money that they do not need to. I also think that if people look creatively at some of the services that are offered to people, particularly work that we have done with mental health service users who have had no support in the community and end up ping-ponging between long stay hospital and back home, having a small amount of money put in per week to keep that person at home, sort out their bills and deal with the issues that are causing major problems will stop that long stay hospital that costs a large amount of money. So I do think being willing to take risks and look at things creatively is the way to go forward and it does not have to be solely about money.

Hazel Roper: I think that the localised assessment process could be considered to be a waste of money. We are hearing from disabled members that where they have had an assessment in one local authority area and move home to another local authority area, the interpretation of the fair access to care services is different in that separate local authority and another reassessment is done. That is a lot of professional time and a lot of stress for that individual and if the assessment was done correctly in the first place, that assessment should be a portable assessment. It is not in the national taxpayers’ interest for that assessment to be repeated. So I think that what the ILA would want to look for from national government is for strengthening of the uniformity and helping local authorities to equalise the implementation of fair access to care. That would not necessarily be about the money.

Adam Penwarden: Which again is what Dilnot said.

The Chairman: Thank you very much for your evidence today. It has been extremely helpful to us. If you feel that there are points that we have not covered, please write to us. Apologies for the unexpected break.

Councillor David Rogers, Emma Jenkins, Linda Sanders and Jonathan Gardam; Tim Cooper; Cynthia Bower, Louise Guss, Hugh Constant and Don Brand

Tuesday 12 July 2011, Q 172–231

EVIDENCE SESSION NO. 5. HEARD IN PUBLIC

Members present:

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

Examination of Witnesses

Councillor David Rogers [Chair of the Local Government Group's Community Well-being Board], **Emma Jenkins** [Senior Adviser in adult social care, Local Government Group], **Linda Sanders** [Co-chair of the Association of Directors of Adult Social Services Physical Disability Policy Network] and **Jonathan Gardam** [Policy Officer, ADASS].

Q172 The Chairman: Good afternoon and welcome to the Joint Committee on Human Rights session on independent living. For the record, could you introduce yourselves, please?

Linda Sanders: I am Linda Sanders, the corporate director of social care, health and housing for the London Borough of Hillingdon. I am here on behalf of the Association of Directors of Adult Social Services.

David Rogers: I am Councillor David Rogers. I chair the community well-being programme board for the Local Government Group, which is the representative organisation for local authorities across England and Wales.

Emma Jenkins: I am Emma Jenkins, senior adviser in adult social care at the Local Government Group.

Jonathan Gardam: Jonathan Gardam, policy officer for ADASS.

Q173 The Chairman: Thank you very much. I begin by asking the representatives of the Association of Directors of Adult Social Services to explain how the legal and policy framework in this country supports the right to independent living.

Linda Sanders: There is a big debate at the moment about the extent to which it does and the extent to which that framework has failed to embrace the right to independent living. We are clear in the sector that we need an integrated, transparent and equitable system that

will enhance the experiences and expectations of people with disabilities, creating a social care system fit for the 21st century. The current framework is changing. We have just received the Dilnot Commission work and very recently the Law Commission work that has been studying over the last few years.

This is a time of health and social care reforms and to correct some of the faults and legacies of the past. The Law Commission has explicitly recognised that the adult social care system has been operating on the framework of the National Assistance Act 1948, the Community Care Act 1990 and so on, with still some remnants almost of elements of the Poor Law, as well as the assessment and care management mechanised structure in terms of assessment care management and approaches to adult social services.

Things like the new vision for adult social care and the *Think Local, Act Personal* concordat—the sector-led framework that highlights a new policy to do with personalisation, partnership and prevention—put us in a different place from where we were even a couple of years ago. There are arguments that the system to date has fault lines in embracing independence, but we are now moving into a context where we are putting people first, embracing personal budgets and empowering people much more effectively. We are in a different place policy-wise, and I hope we will be in a different place legislatively, too.

Q174 The Chairman: Are there any specific areas where you would suggest amendment to comply with the obligations of the UN convention?

Linda Sanders: I do not know. I think I would have to consider that further. I am not a lawyer and I do not know enough technical detail to advise the Committee on that this afternoon. Perhaps we will reflect on that further and come back with any additional reflections.

Q175 Baroness Campbell of Surbiton: My question is to both of you. We have received quite a lot of evidence from groups including the Disability Rights Partnership suggesting that there is a gap between policy intentions, in particular the Independent Living Strategy and other policy documents such as *Think Personal, Act Local*, and the everyday experience of disabled people on the ground. That gap is coming up again and again. Can you comment on this suggestion? What do you think is responsible for creating this gap and what steps do you think need to be taken to close it?

David Rogers: I am happy to start on that. The content of your question illustrates a wider point across public services as a whole. Heretofore, there have been specific initiatives that address a part of a wider problem or issue. The necessary joining up has not worked as well as it might do. We all need to do better at that. The best way to do that locally, as a response that local government can give, is to ensure that we involve users of services as much as possible in the design of those services to ensure that the gaps that some may have identified are, to a certain extent, addressed and we can do what we can.

To look at it in a wider perspective, the Local Government Group feels very strongly that the totality of public resources for an area should be much more capable of being pooled. This is the Total Place approach that you may have heard about, or community budgeting. We then see that reflecting the needs of a specific local community and the individuals within it. Maybe we have a long way to go on that. There are certainly good examples that we can learn from, but I understand the point that you are making and it is incumbent on all of us to do rather better.

Q176 Baroness Campbell of Surbiton: Would you agree that there is a gap?

David Rogers: There are cliff edges between particular services, yes, because of the nature of the current arrangements, as I explained.

Linda Sanders: I think I would say that it depends. Some disabled people have given evidence to you, and would say to us, through feedback within our user involvement systems locally and nationally, that there are some areas geographically and some service areas that do a lot better than others. Undoubtedly there is a gap. There are also some hugely positive examples of good and improving practice that empowers people to lead independent lives within the community. The Committee is probably aware that through embracing personal budgets, for example, there are some very impressive case studies of how in adult social care, in partnership holistically with community voluntary organisations, good access to universal services locally has helped to transform people's lives. There are wonderful examples where people who have been living in institutions, sometimes for decades, have been supported to move into supported housing with a personal budget and personal assistance. Their lives have literally been transformed. They have never had a front door where they can receive their own post through a letter box before. They have never had a fridge that they can keep a pint of beer in, or something. There are some fantastic examples of cross-sector, joined-up working, but we do not always get it right. Some of the huge financial pressures and, understandably and rightly, the increasing aspirations of people with disabilities mean that there is a gap in many instances. Should I add something about fair access to care criteria?

Baroness Campbell of Surbiton: If you want to.

Linda Sanders: Increasing numbers of authorities—78% of councils—now have fair access to care criteria, where we are only able to meet substantial or critical needs. That has been a deteriorating situation over the years. It was 70% in 2010-11 and this year it is 78%. There are 4% of authorities, which I know is a small number, that are only able to meet critical needs. So there is something whereby large numbers of people will be very disappointed because of the eligibility criteria that are affordable within local authorities.

Q177 Baroness Campbell of Surbiton: Would you say that that then has an impact on one's ability to have independent living?

Linda Sanders: I would say that there is a mismatch of expectations. People hope and expect that adult social care will be there for them at a time of need, or sometimes at a time of crisis. Sometimes the means-tested system is such that they might not be eligible for the levels of support and personal budgets that are afforded to those with lower levels of income. There is a lack of understanding in the community and within society about the limitations on services—not universal services or information and advice, but tailored personal care services being predicated on ability to pay.

Q178 Mike Crockart: One of the other concerns that has been brought to us by a large number of groups that we have spoken to already is the Equality Act. In particular, the Disability Rights Partnership told us that “the Equality Act seems to be seen as a bureaucratic burden rather than as being integral to delivering services in support of disabled people”. This question is mainly aimed at Councillor Rogers. Is that your experience? What role do you think the Equality Act plays for local government in the context of delivering equal access for disabled people?

David Rogers: If I may say so, I am a little surprised to hear the question phrased in that way. When the single Equality Act was envisaged, we welcomed that concept and we welcomed the passing into law of the Act, partly because it brought previously separate regimes together. To that extent, it might have reduced multiple obligations under different arrangements. It is fundamental to an understanding of the diverse range of local communities and all those, including the specific individuals and groups you mentioned, who live within our communities. If one steps back and thinks about it, I do not see how we can

be planning for services of any description, including the specifics that you mentioned, without an understanding of those needs within our community and the responsibilities that go with that. I am sorry that that particular group feels that way. It is certainly not a view that I share and I do not believe it is shared by the vast majority of those in positions of responsibility in local government.

Q179 Mike Crockart: And how does it impact on you, particularly in practical terms?

David Rogers: In other work within the Local Government Group as a whole, we have devised equality frameworks for different sections of the public sector. Those are now firmly in place in most of our member authorities. They are seen as a useful tool to ensure that we are responding in the way that I described in the first part of the answer. I do not see it as a burden; I see it as something that is fundamental to the design and delivery of services.

Q180 Mike Crockart: Perhaps I can widen this out to others in asking a follow-up. Were any of you consulted by the Cabinet Office on the inclusion of the Equality Act 2010 in its red tape challenge? Do you have any views in general on the branding of it as being red tape?

David Rogers: I do not think we were specifically consulted.

Linda Sanders: I am not aware that we were. Similarly, while I would not pretend that I am a legal expert within adult social care, the fundamental principles in the Equality Act are wholly compatible with the values underpinning adult social care. Similarly, I would reinforce Councillor Rogers's perspective; it is not my experience that the Act is perceived as a bureaucratic burden. In looking at how we are reshaping and redesigning the services, equality impact assessments are a useful tool and a check and balance that we are truly embracing and we are carefully considering their impact on some of the most disadvantaged and vulnerable people in the community.

Q181 Lord Lester of Herne Hill: In view of the great practical experience that you and your organisations all have, have you made submissions in the consultation on these issues, putting forward the views that you have kindly given to us today, so that the Government understands where each of you and your associates are coming from, since, as you know, there is the opportunity for you to do that before the Government decides whether to do anything at all?

David Rogers: We could certainly consider doing that. I made the point that we welcomed the Act when it was introduced, but if you are talking specifically about the Cabinet Office consultation at the moment, we will take that away and consider whether we should do that.

Lord Lester of Herne Hill: You have not got much time left, as you know.

Q182 Baroness Stowell of Beeston: My first question is to ADASS, which I think is you, Mr Gardam. Is that right?

Linda Sanders: I am here on behalf of the disabilities policy committee of the Association of Directors of Adult Social Services.

Baroness Stowell of Beeston: I will ask the question and you can tell me who is the right person to answer it. Following on from what you have just been talking about, but referring to a different Act, I wonder what the implications of the recent High Court decision to quash Birmingham City Council's decision on funding for only those with critical needs, in the context of the 1995 DDA—presumably you are familiar with the case that I am referring to—will be for your members in terms of how they make their decisions on funding from now on. I am particularly picking up on the point that you made a little earlier about people's expectations and that sort of thing.

Linda Sanders: I think I should probably desist from saying too much specifically about the Birmingham case, because it is still ongoing and further consultation is happening in Birmingham. The context that we have seen in ADASS has been very much to do with recognising the underfunding relative to demand, recognising the archaic legal framework within which we have been operating, welcoming the proposed reforms, which are timely, and recognising the importance, I guess, of a sectoral and political consensus from here on in seeing through the reforms, the Dilnot recommendations and so on.

Councils feel in a bit of an invidious position. Within adult social care services, we are seeking to contribute, as all services are, in focusing on efficiency, managing demand better, managing commissioning more effectively and managing the support systems better. As many of our savings contributions as possible are to do with doing things differently, shifting the balance often from traditional and more expensive forms of care in care homes to supporting people to live independently, which is normally what they want to do anyway, given the chance and the opportunity. Rather than sweeping people into a system and sometimes creating dependency post-hospital discharge or on acquiring disability, we are focusing on reablement services, which are much more cost-effective because they help people to be independent and get back on their feet rather than providing long-term care.

As a sector we have sought to critically examine how we have done things traditionally to date and tried to embrace new things, such as telecare. Access should be for anyone in the public who needs that sort of system at home, rather than being contingent on someone who only has critical needs. There was a report in the last week on that. The Birmingham case highlights the growing use of legal challenges, which is of some concern to us given the financial constraints. It feels a bit as though we are between the devil and the deep blue sea.

Q183 Baroness Stowell of Beeston: Do you feel sometimes that it is almost impossible to square this circle?

Linda Sanders: Yes. It is a tough challenge at the moment.

Baroness Stowell of Beeston: I think it is important that you feel able to say that. There are almost conflicting demands being put on the system at the moment. Coming to this Committee today, I do not want you to feel that you are not able to say that. It is important that you can say it if you feel that.

David Rogers: Can I add something that ties up with that point? The way we look at it in local government was illustrated when the Prime Minister came to the Local Government Group's annual conference less than a fortnight ago. He acknowledged that, as we have known for a while, local government is the most efficient part of the public sector. We have demonstrated year after year across our services, but in adult social care in particular, that we can deliver improving services for those who are eligible to receive them. But of course that does not mean everybody. It has never been free for everybody and we are all fully aware of that.

On the funding situation, obviously we have made considerable savings over a number of years. That has led to the efficiencies to which I referred. This year's situation is particularly difficult. As you will be aware, the funding for local government was front-loaded and therefore we are in a worse place than some other parts of the public sector. Despite the additional resources that the Department of Health put in, the overall position for local government was not good. I think it is also true to say—I do not have the figure at my fingertips, but I can provide it if it would be of interest to you—that local government across the country, collectively, puts in a good deal of money that is directly raised from its local taxpayers through council tax as well as the money that comes from government sources. This is not an issue that we are unaware of. You are quite right to say that we should say

how we feel. We do feel that we are efficient and that we are improving services, but it is a very difficult position because of rising demand and rising expectations.

Linda Sanders: If I may add, in this financial year adult social care is contributing £1 billion of savings across England.

Q184 Baroness Stowell of Beeston: You have answered the fundamental point, but I have a couple of other questions. Because of these conflicting demands that are being put on you, how are you going about prioritising the services that will maintain people's right to independent living in the context of this current budget situation? Is there a way that you can explain how you are trying to manage this?

David Rogers: I can explain it from a locally elected councillor's point of view. The advantage of that dimension of local democracy is that the vast majority of us live in the communities that we represent and therefore we are in touch not only with the needs of those communities as a whole, but with many individuals within them, including those who have specific needs of the sort that this Committee is most interested in. The issue of balancing all those conflicting demands is not a new one. It is a more difficult one, I would be the first to accept, when finances are constrained in the way that they are currently, but the principle of being aware of a vast range of different needs and trying to reconcile those within the limits of what we are able to do is something that I would feel my colleagues are relatively well experienced at doing. Linda may have a professional view of this, and of course there are certain requirements that have to be undertaken in that sense, so it is probably best if I ask Linda to elucidate that point.

Linda Sanders: Clearly, one approach which I am sure the Committee has focused on is targeting people in greatest need. That has to be alongside recognising our responsibilities to provide more timely, more accessible and better information and advice, not just relying on local government or adult social care, but utilising community resources, the voluntary and community sector and libraries and so on. That can sometimes utilise resources that can be better targeted within local authorities. Creative use of funding streams is something else. There has been a 13% reduction since 2005 in the number of people aged 18 to 65 who we support in care homes. That is a direct consequence of the fact that we have much more sought to embrace supported living. A number of directors of adult services also have responsibility for housing, either directly or for housing strategy. Over the years we have sought to ensure that we are developing extra care housing models, both directly and working with registered social landlords, and more supported living options including supporting people to have a broad canvas of options so that they can live in a range of different settings to support them within the community. That shift in the balance from assuming that people with certain levels of ill health and disabilities need to be in care homes compared to being more effectively—and usually more cost-effectively—supported at home has been decisive and compelling and will continue.

Q185 Lord Dubs: My question is directed in the first instance to Councillor David Rogers. A key theme of the evidence we have seen so far is the risk that independent living, and disability equality more widely, can be placed in a silo marked “social care” and then ignored by other decision-makers. We have been told that a lack of cross-government thinking is a problem at both local and national levels. Do you agree with that? It is a tough one.

David Rogers: Again, from my experience over many years as a councillor, that has been my greatest frustration. Those colleagues with whom I work in a professional capacity see things from the basis of their particular profession, their training and the way they have done things historically. That is changing. In local government, we are much better at making those links across different service areas than government departments are. This has evolved over a

number of years through things such as local strategic partnerships that have attempted to do that, and now with the proposals for health and well-being boards. To my mind, that is not just about bringing health and social care more closely together in a particular area, but also about recognising that wider well-being, or whatever term we might wish to use, encompasses not just those services but things such as transport, the environment that people live in, learning opportunities throughout life and access to culture. Really, there is nobody better placed than the local authority to hold the ring to ensure that that is brought together to the best of our abilities. It is going to be different in each area, which is essentially why we take a local approach to these things.

Q186 Lord Dubs: Thank you. You have almost anticipated my supplementaries, but I will ask them anyway. Do you have any examples of how local authorities can integrate a positive approach to independent living across each of their areas of responsibility, particularly in connection with access to the community, housing, planning and transport? I know you have partly mentioned this, but do you want to add anything?

David Rogers: I do not feel that I have the specific examples here today, but again I am very happy to see what we can do to provide the Committee with some specifics on that.

Q187 Lord Dubs: You have also mentioned the health and well-being boards. Do you see a particular role for them, and the power of the local authority to promote community well-being or community budgets?

David Rogers: Yes. That is fundamental. That is why we have been very much in favour of those proposals in the Health and Social Care Bill. I accept that other parts of it have been slightly more controversial. That debate is ongoing. The proposals to have health and well-being boards have the potential not only to bring about the greater integration that I have already spoken about, but also to bring greater democratic legitimacy to local spending and commissioning decisions—not to the fullest extent, because there can be a majority of councillors on the board if the legislation stays as it is at this point, but there might not be, and in any case there are other views that quite properly need to be taken into account. But the potential is quite clearly there and I very much hope that, among the 130 of our 150 relevant council members who are embarking on this process, the vast majority are already getting on with setting up their health and well-being boards in advance of the legislation, because they see it as an opportunity to do just the things that you are asking about.

Q188 Lord Dubs: I must say that local government has moved on a long way since I was a local councillor. My last question is that some witnesses have called for certain local authority funds connected with independent living to be expressly ring-fenced—for example, any funding for accessible housing or transport or social care. Is there any reason why funds determined for a particular purpose should not be ring-fenced?

David Rogers: Again, this links back to my earlier point about the Total Place approach or community budgeting. If funding streams are ring-fenced and particular services are then designed around those and only those, that is in effect a barrier to the greater integration that I would certainly like to see—and I imagine from your line of questioning that you would like to see it as well. We do not support ring-fencing as a principle. There may be limited occasions when others deem it to be necessary, but our principle is that the maximum amount of public spending in an area should be capable of being pooled in line with common objectives across all services.

Q189 Lord Morris of Handsworth: My question is primarily to the local government representatives. I have a primary question and a couple of supplementaries. Although the

ultimate responsibility for compliance with the UN convention lies with the UK Government, the front-line implementation of the rights it protects is often undertaken by local government and other agencies. Do you think that there is an effective dialogue between central and local government on the implementation of domestic and international human rights standards for local decision-making?

David Rogers: I agree with your question setting out the situation. Ultimately it is for the Government, but we are always happy to have an open dialogue with the relevant departments of central Government, with Ministers, with civil servants and with any relevant individuals or bodies. I have no doubt that, as with anything else, we are looking to improve how that operates in practice as time goes by. None of us should be seeking to stand still. We should always be seeking to improve that sort of arrangement.

Q190 Lord Morris of Handsworth: Let me broaden the question with my first supplementary as an example. Have any local authorities expressed concern to central Government about the potential impact that funding cuts and changes to policy could have on their ability to support disabled people to enjoy their rights, including their right to equal treatment and independent living? If so, how have your views been received?

David Rogers: I am not aware of any specific representations that have been made in that manner, as in your question. However, not just this year but in previous years we have most certainly made representations about the overall resources that are available to the social care system as a whole. Clearly, that would have an impact on all service users, including the ones that this Committee is most interested in. To answer on whether it has had any effect, the Department of Health response in the current year's settlement was an example of it having an effect, or of that gap between available resources and expectations being recognised by DH. But as I have already said, that was more than offset by reductions in the overall funding for local government.

Q191 Lord Morris of Handsworth: The Secretary of State for Justice and the Human Rights Minister told us that it would be difficult to assess the impact of policy changes and funding cuts on disabled people until those cuts were in place. Do you share that view?

David Rogers: We should always try to assess the impact before decisions are made. That is pretty fundamental to any proposed service changes. Again, I would make the general point that any mechanism of that sort, or any way in which we go about the things that we have to do, is always capable of improvement, so I am not saying it is perfect, but I hope that it would be the intention to make that assessment in advance.

Q192 Lord Morris of Handsworth: Have you sought to promote impact assessment before policies are implemented?

David Rogers: Yes, that is pretty standard practice. My colleague will perhaps be able to give you an example of how that is done from a director's point of view.

Linda Sanders: Certainly, the utilisation of the undertaking of equality impact assessments is mainstreamed and integral to how we approach change now within local government. I indicated earlier that in my experience, with positive leadership about the benefits, those benefits are recognised and the discipline is valued.

In terms of the wider impact of things like the cessation of applications to the Independent Living Fund, to housing benefit and to various welfare Bill reforms, as a disability committee we work closely with 50 to 60 major voluntary and community sector organisations and have had regular meetings with DWP and the Independent Living Fund. We have raised a number of issues and concerns. We cannot always quantify the holistic impact on people with disabilities, but for example we have raised the issue about the Independent Living Fund.

I think there are about 20,000 people in receipt of ILF at the moment at a cost of about £350 million across the UK. We are aware that the cessation of new entrants means that by 2015 that will be £120 million of savings. We have made representations about whether that could be transferred to local government to minimise the impact on people with disabilities. But we are also mindful of the fact that the criteria are quite different. ILF has been able to do some things that local government has not always been able to do, in terms of criteria for funding.

Q193 Lord Lester of Herne Hill: I am quite puzzled by the Government's response. I should just admit I am a lawyer. I always thought that public authorities had to carry out an assessment of the adverse disparate impact, for example on the disabled, before they introduced a practice or a policy, otherwise they would finish up in court on a judicial review, unable to defend what they had done. When you, as public authorities, are trying to decide what to do, do you carry out an assessment beforehand so that you are able to stand up in court if necessary and say that we have done it and this is the basis on which we proceed?

Linda Sanders: Indeed we do. As I have indicated, it is common practice, when we are looking at change of policy in particular, to undertake an equality impact assessment in local government. I was referring to central government changes, on which I assume that central government departments have undertaken equality impact assessments either together or individually as departments. It is common practice within local government.

Q194 Baroness Campbell of Surbiton: I would like to explore the closure of the Independent Living Fund. You would not expect otherwise. A number of organisations and individuals have told us that the closure of the Independent Living Fund will severely curtail access to independent living for disabled people with the highest support needs. This is for both of you. I would like to know how you view this fear. Will local authorities be able to meet the needs previously met by the ILF grants? Given the increased pressure on community care budgets, what measures are local authorities taking to ensure that the ILF closure does not have an impact on the UK meeting its obligations to a right to independent living under Article 19?

Linda Sanders: That is a hugely challenging and difficult question. We are already experiencing people coming to us in adult social care who previously would clearly have gone to the Independent Living Fund. With the majority of authorities having eligibility criteria of substantial or critical, there is little doubt that there will be many people who cannot now be assisted in the way that the Independent Living Fund was able to assist people, because the eligibility criteria were different and lower and they were able to provide support in a range of ways that local government now cannot, because of our criteria. So I think there is an adverse impact. The future administration of the fund is uncertain. There is little doubt that people have come to us in local government because they cannot go to ILF. Sometimes there are packages where there was support from the local authority, and ILF topped that up and contributed to a more holistic package. I am sure there will have been adverse consequences because of that, too.

At the same time, we are in discussions with people from ILF who remain profoundly committed to continuing to support those 20,000 people still within the system—that is absolutely evident. But I gather there are further discussions about the succession planning for that, the use of the savings and how there is going to be a more integrated system in future in local government, presumably, for transitional arrangements for people who are currently in receipt of ILF.

Q195 Baroness Campbell of Surbiton: You did not answer quite an important part of the question. Do you feel, therefore, that the UK will not meet its obligations to the right to independent living in terms of Article 19?

Linda Sanders: I do not know that I can unequivocally answer that.

Baroness Campbell of Surbiton: Would you say that it would have an adverse impact?

Linda Sanders: I think that if there is less money in the system for people with disabilities, then there will be an adverse impact for some.

Q196 Mike Crockart: It has been quite clear in the evidence that we have received that social care is becoming an increasingly complex landscape, whether it is through devolution or through an increasing localism agenda. It seems to be bringing in discrepancies between the ways in which different local authorities deliver adult social care. Some of the evidence has indicated that this has meant that disabled people's human right to freedom of movement is compromised. Do you agree? Despite the fact that I really dislike the phrase, do you think that we have a postcode lottery, and that that is an inevitable consequence of local accountability and local decision-making?

David Rogers: We certainly support local decision-making and we never use the term that you have just used, but I understand why you use it. The slightly more helpful answer is that what we support and have supported for several years now is that there should be a national system of assessment, so that the needs of an individual are recognised in the same way, wherever they are starting from and wherever they live currently, but how those needs are met should be a local decision. That will vary on the particular community in which they live and the community assets, if you like, that are available to support those needs in that area. Consistently, and long before the Dilnot report or the Health and Social Care Bill, we have argued for a part-national, part-local system to seek to recognise the points that you have made.

Linda Sanders: Certainly, from the ADASS disability committee, we have been working recently with the National Union of Students, who have said very strongly to us that they feel that a national portable assessment system would be hugely helpful and important for them and that they would like the future arrangements to build that in. There are now 338,000 personal budgets in England, as at just a couple of months ago. The figure has doubled compared to last year. That new approach and mechanism, which gives huge flexibility to the individual over the choices that they make and the control they have over the support that they commission, will lend itself much more to a portable system.

The Chairman: Thank you very much for your evidence today. I am sorry if we seem a little bit rushed, but there are lots of questions to ask you. If I may, could I ask you to respond to some written questions that we will send you? If you feel that we have not covered everything following those questions, please submit a further memorandum.

David Rogers: We will certainly do that, and the specifics that we mentioned during the session.

The Chairman: Thank you for your co-operation.

Examination of Witness

Tim Cooper [Director of the Office for Disability Issues].

Q197 The Chairman: Good afternoon. For the record, will you introduce yourself please?

Tim Cooper: Good afternoon. My name is Tim Cooper and I am the Director of the Office for Disability Issues.

The Chairman: Thank you, Mr Cooper. The first question is about the co-ordinated approach to policy implementation. Many witnesses, either by writing to us or through our evidence sessions, have emphasised the importance of a joined-up approach in order to achieve better access for independent living. Can you describe what the Government are currently doing to integrate the obligations of the UN convention into their work across government departments and your role in all that?

Tim Cooper: Perhaps I should quickly outline the role of the Office for Disability Issues, which is a cross-government unit based in the Department for Work and Pensions. It supports the Minister for Disabled People with an across-Whitehall remit. Although we are based in DWP, we work right across Whitehall with most departments and a few agencies of government outside Whitehall.

To summarise our role, it focuses on three things. The first is around leadership on disability, which includes supporting the Minister, ensuring that the right parts of legislation are completed, building the evidence base and taking responsibility for co-ordination on the UN convention. Secondly, it is about working alongside Whitehall departments and building their capability in terms of delivering services and policy for disabled people. Thirdly, it is around innovation, including helping departments to think about new and different ways of developing policy, particularly delivering services.

Within that context, we are what is known as the focal point in government for the UN convention. Over the first two years, we have particularly focused on working with Whitehall departments to ensure that they are aware of the provisions of the convention. Secondly, we have done work directly but particularly in partnership with the human rights commissions and disability organisations to raise awareness of the convention among disabled people directly. Our focus at the moment is around preparing the Government's report, which has to be submitted to the UN detailing progress on implementation this year. Our co-ordination function is around ensuring that departments are aware of the provisions and then working with them on a bilateral basis to help them understand the practical implications for themselves. But we have been quite clear that our role is not to do, but to support, guide and advise.

Q198 The Chairman: I think you have answered my supplementaries, but perhaps I can ask them in a different way. Given your particular crucial role as the focal point of the convention, if there were concerns in other departments, how would you go about addressing them?

Tim Cooper: If other departments were expressing concerns about the convention—

The Chairman: No, I mean the other way round—that is, if you felt that there were concerns about the way in which they were not implementing the convention.

Tim Cooper: I would see that as part of our capability-building role. Where that might sound a posh term, it is essentially about building working relationships with the key officials in individual departments so that they can feel that they are able to come to us and express their concerns and we can act as a sounding board. We can also put them directly in touch

with disabled people or other disability organisations that might be specialists. Ours would be a troubleshooting role; for example, if they came to us directly or if others raised concerns, we have the ability to go to those individual departments and say, “This issue has been raised. We think you might like to tackle it in this way.”

Q199 The Chairman: Finally, what has been the experience of what is called the Right to Control Trailblazers in terms of what they told you about these issues and how have you gone about implementing the issues that they raised with you?

Tim Cooper: The Right to Control Trailblazers are a particularly exciting part of policy, which links very much to the issue of how we join up services at the front line for individual disabled people. We are in the relatively early stages of seven trailblazers testing how the Right to Control will operate. Some went live in December and some as late as April this year. We are expecting interim evaluation towards the end of this year.

The early learning coming from the Right to Control Trailblazers focuses around practical ways of streamlining assessment and collection of information about the needs of disabled people and about the notion of a joined-up support plan, particularly across housing, social care and employment. We are starting to move into really pushing cultural change. For example, we are seeing in some areas user-led organisations starting to take on some of the direct delivery of the support functions that previously local authorities had delivered themselves.

This whole issue of involving disabled people has been fundamental right from the beginning of Right to Control. That is one of the reasons why, whatever the ultimate outcome of the evaluation, there will be a huge amount of learning that we get from Right to Control in terms of how we deliver cultural change at the front line and how we can, on a practical basis without a kind of revolution, evolve systems to allow the customer experience at the front end to be much more straightforward.

Q200 Lord Lester of Herne Hill: I do not understand how you can do your job effectively when the Minister has told us that it would be difficult to assess the impact of policy changes and funding cuts on the disabled until they are in place. If the Government find it impossible or difficult to do that, how can you do your job in the way that you have been describing it? Do you not need to have proper what you would call analytical tools to be able to do your job properly?

Tim Cooper: I am not aware of the context of the particular Minister or the comment. From our experience of working with departments in the development of policy—we work with some reasonably closely—they undertake equality impact assessments as part of the process of developing that process. What may have been meant is that one cannot produce the final assessment until the policy itself is complete. So it is an evolutionary process in that the equality impact assessment process runs alongside the development and the implementation of the subsequent policy. We are very clear that it is not our job to do people’s impact assessments for them, but part of our job is to help departments to think through how to carry out those assessments and to act as, again, a sounding board once they have done the assessments to offer comment on how those assessments might look.

Q201 Lord Dubs: Mr Cooper, as you know, the independent living strategy is a cross-government strategy and contains commitments made by government departments responsible for housing, social care, education, training, employment and transport. Has a similar cross-governmental approach been taken as regards the Government’s obligations relating to the UN convention?

Tim Cooper: Absolutely. The UN convention has very much been a cross-government piece of work. The focal point is located within the Office for Disability Issues but the responsibility for taking on board the practical implications of the convention is very much down to individual departments. Our role is to make sure that they are fully aware of their obligations and, in that capability-building way of which I spoke earlier, our role is to help them to embed the issues arising from the convention in their policy-making and to support them in the wider implementation.

The cross-government approach is very much evident at the moment in terms of preparing a report for the UN. Individual departments have prepared their reports. We have synthesised, edited and gone back and discussed those reports with them. That draft report has now been published so that people can make comments on it. We are now in the process of talking to individual departments about the comments that have been received on their parts of the draft. It has been a good piece of cross-government work.

Q202 Lord Dubs: You mentioned cross-government approaches. Are there any barriers to working across government in delivering independent living for disabled people?

Tim Cooper: Certainly there are barriers, but part of the ODI's job is to suss those barriers out and work ways around them, and, more importantly, to get individual departments to recognise those barriers and to work ways around them. Inevitably, the nature of government means that you are very focused on your particular policy area and budget area, but that does not always support good, strong cross-government working, even at a policy level or a grassroots level. The Right to Control, which we have just touched on, is a good example of bringing together the Department for Work and Pensions, the Department of Health and the Department for Communities and Local Government, as well as local authorities and indeed organisations outside government. If you will excuse the pun, it is blazing a trail in terms of how to get round some of those practical barriers.

Q203 Lord Dubs: Do you think that all departments are equally committed to implementing this strategy? It is your job to see that they do.

Tim Cooper: No, clearly. One important part of the independent living strategy was getting wider recognition of independent living being not just about where you live but about all the changes to society and the support services that helped you to live a fulfilled and independent life. Getting that broader definition has been one of the positive things to have come out.

I think that individual departments still see the delivery of independent living through the prism of their policy area. There is probably more that we can do to help them to understand that, if they change one area of policy in their department, there may be knock-on effects for a sister department down the road. That kind of brokerage is part of ODI's role.

Q204 Lord Dubs: The draft report of the UN talks about a new disability strategy. Will this replace the existing independent living strategy?

Tim Cooper: The independent living strategy, to my mind, was in two parts: the philosophy and ethos of independent living, which live on and are, in a sense, a fundamental part of the strategy; and a set of practical actions to take that ethos forward. We have deliberately front-loaded those actions over the first two years, so the practical action plan part of the strategy is largely complete.

The approach now is to think about how to ensure that the ethos is embedded in individual departments' strategies. You can see a lot of the key elements of the independent living strategy in the Department of Health's provision for social care. We are working on a new

disability strategy that will tell the story of the Government's approach on disability across government, and more practical actions around independent living will be incorporated into that.

Q205 Lord Morris of Handsworth: Mr Cooper, you have defined your role as supporting, guiding and advising. Ultimately, responsibility for the implementation of the convention lies with central government. Witnesses have told us that a key problem is the lack of consistency between local authorities and across different parts of the UK. As the national focal point for the convention—I can see that it is being manifested in you—can you describe the mechanism that is in place for you to work with local authorities and the devolved Governments?

Tim Cooper: As I said earlier, we are just two years on from ratification of the convention. It would be fair to say that ODI's focus in those first two years has been very much on Whitehall departments and on working with partners in raising awareness among disabled people. That is where the bulk of our energy and effort has gone. The question of how local authorities or other local delivery agencies of government take it up is important, but it is coming more to the fore in this second phase of implementation.

There are two points. One is that individual Whitehall departments should take responsibility for ensuring that their local delivery agencies are fully cognisant of the implications of the convention and are taking it forward. That includes local authorities and others. However, it is fair to ask whether the ODI should reflect on whether, over the next two years, there is more that we can do to support departments in thinking about how to take the convention out to local authorities and other agencies.

Q206 Lord Morris of Handsworth: I am a little perplexed. The principle of the Government's responsibility in relation to the convention is accepted but you seem to be placing, perhaps correctly—I do not know; we are looking for you to distil the issue for us—a lot of emphasis on the departments. I recognise that that is a starting point but ultimately, as I have said, the convention is the responsibility of the Government. Can you describe what steps are being taken to involve the devolved Governments and local authorities in preparing the draft report for the UN?

Tim Cooper: I am sorry. I omitted to address the issue of the devolved Administrations in my answer. We have liaised with officials in the devolved Administrations on taking that forward and they have responded to the report with their own sections. We have also worked—again, quite closely—with the independent commissions in the devolved areas in terms of the human rights commissions. I would say that we have an established working relationship with the human rights commissions, as we do with the devolved Administrations. That works as it does for Whitehall departments. As I said earlier, we have not done any direct work with local authorities at this point.

Q207 Lord Morris of Handsworth: Let us take a practical point, because this is very important. How would you react if a local authority contacted you to raise concerns about the impact of national policy on its obligations under the UN convention—for example, arguing that the cap on housing benefit might impact adversely on its ability to house disabled people effectively, which is a right enshrined somewhere?

Tim Cooper: Again, our role in that circumstance would be to broker that discussion. It would probably be a three-way discussion between the DCLG, as the department responsible for local authority funding, the DWP, which is responsible for the benefit cap, and the local authority, whether directly with the local authority or with the trade body or association of local authorities. The ODI as a body does not have the wherewithal to

intervene directly in that situation, but it is about ensuring that the people who have the power to take the actions are brought together to address the issue.

Q208 Lord Lester of Herne Hill: Can I ask a supplementary question? You have lost me, Mr Cooper, because you have not given us any practical illustration of what you do. Can you take one example to serve for all where you have dealt with this issue and tell us exactly what has happened without necessarily identifying the party? Just talk us through one practical example so that we know that it is not just, as it were, verbal.

Tim Cooper: Just so that I fully understand the question—and I am sorry if I am not being clear about what we do—you want me to elaborate on how the ODI works with individual—

Lord Lester of Herne Hill: Just take one example to show us what difference you have made.

Tim Cooper: We have worked with the Department of Health, for example, running a number of regional road shows, as they called them.

Lord Lester of Herne Hill: I mean a practical example where a problem has arisen and you have been able to tackle it and produce a practical solution.

Tim Cooper: At this stage, we have not been directly involved in issues of that nature. Individual departments and outside agencies have not brought those sorts of practical issues to our attention.

Q209 Lord Dubs: What evidence do you have about awareness among private residents of care providers of the Human Rights Act 1998? Has the recent extension of the Act to them had any impact?

Tim Cooper: The policy lead on that issue rests with the Department of Health, so I am talking a little bit out of my direct area of responsibility here. However, I would expect that the Department of Health, through the Care Quality Commission, would make the provisions of that Act perfectly clear to people operating in that sector. I would also come at that question from a different angle, as someone who has previously run an organisation providing residential care. There is a strong obligation on the providers to understand the legislative framework in which they are working and to ensure that they are fully taking forward both the spirit and the detail of that legislation.

Q210 Lord Dubs: I suppose I am asking about a specific example again. What action have you taken to increase awareness of the implications of the Human Rights Act for residential care providers? Do you think that the Government should be doing more?

Tim Cooper: As I said earlier, the Office for Disability Issues is not directly responsible for that kind of activity, which is why I would see that question as one that is perhaps best directed to the Department of Health.

Q211 Baroness Campbell of Surbiton: Could the UN convention be a useful tool for raising awareness about human rights in general and independent living, in particular among service providers?

Tim Cooper: The UN convention is an extremely useful tool in a whole raft of different ways. One of the very positive benefits that we have seen in a relatively short period of two years is the raising of awareness of the rights of disabled people, and there is a stronger use of human rights language in this area than we had before the convention came in. In terms of the detail of your question and in terms of working with individual providers or groups of providers, the convention offers a powerful framework in that regard. I appreciate the Committee's frustration, but the first two years has very much been around embedding

within national government a good understanding of what the convention is about and trying to start the process of raising awareness with disabled people. Taking the convention on in terms of the practical ways that you describe is very much the sort of thing that we can now move on to.

Q212 Baroness Campbell of Surbiton: Do you have a plan to do this?

Tim Cooper: Not at the current time. Our focus at the moment is very much on getting the draft report finalised and sent to the UN. That, as you will appreciate, is quite an extensive piece of work. That will then allow us to move on to the next stage of work around implementing the convention.

Q213 Mike Crockart: You have talked about your role in capability building, as part of your role as a government focal point, particularly in relation to Article 4 of the convention. I am trying to focus on concrete terms. What does this mean for ensuring that disabled people are involved in your work and how do you encourage the full participation and involvement of disabled people in the work of other departments and local authorities?

Tim Cooper: Co-production is very much part of the ethos of ODI, by which I mean the involvement of disabled people right from the beginning of the development of the policy through the lifecycle. In practical concrete terms, and in terms of the UN convention, we have worked with the United Kingdom Disabled People's Council, which has convened on our behalf a group of disability organisations that have worked alongside us in promoting the convention to other government departments and in starting to prepare the draft report. The council has been involved in every stage of that. We have established a body called Equality 2025, which comprises 10 disabled people who are public appointees. It acts as a body that provides strategic advice to Ministers and senior officials—not just within ODI and DWP, but right across Whitehall. They are very much involved in working with the Department for Education for example, on the SEND Green Paper. We have tried to embed that principle of co-production in our work with a number of different departments.

As regards the Right to Control, we established an advisory group of disabled people to support us right the way through that process. On a smaller practical basis, we have been doing some work with the Department for Culture, Media and Sport around the legacy from the 2012 Games. Part of our role there was to make the link for that department with disabled people and disability organisations, so that they could gather the thoughts and aspirations that disabled people had around the legacy from the Games. It is a piece of work that ODI does quite successfully and there are some very tangible examples.

Q214 Mike Crockart: What sort of responses are you getting from departments? Is it a wide spectrum of responses?

Tim Cooper: Departments are keen to engage. They are often a bit lost on how to go about doing it. Our role, if I might put it colloquially, is very much about the hand-holding at the early stage in terms of helping them to understand who the main disability organisations are and how they can engage directly with disabled people. One of the other innovations over the past couple of years has been something called Network of Networks, which is essentially a grouping of a range of different local disability organisations, some of which are quite small—grassroots organisations are included within that—that have agreed to act as consultees for departments on a range of issues. We will put to their lead organisation a list of, say, 20 questions on which a department wants the views of disabled people. The organisation then cascades that to its members and co-ordinates it back to us. We now have a range of practical mechanisms to help other departments to engage with disabled people. Is it a finished job? By no means. We still need to embed it into the organisational psyche

that people think about that right at the beginning, instead of perhaps halfway through the process.

Q215 Baroness Campbell of Surbiton: Can you describe the mechanics behind the preparation of the UK draft report to the UN, including the steps taken to involve disabled people in each part of the UK? I particularly want to know whether you think a four-week to five-week consultation period on the UK draft report to the UN is consistent with the obligation in Article 33 to involve disabled people in the monitoring process on the implementation of the convention.

Tim Cooper: As I indicated earlier, right from the beginning of the process we have engaged with disabled people, and we have particularly looked to building a relationship with the United Kingdom Disabled People's Council to facilitate that process. It has chaired a group that has been integral in the process of considering how we would prepare the draft report. The council has been involved in reviewing the consultation responses. As you will be aware, we have extended the consultation period to 25 July. There has been a reasonable period of time, taking into account the fact that it is not just during the consultation period that disabled people have been feeding in their views but during the whole 18 months in which we have been working on the draft report.

Baroness Campbell of Surbiton: But the consultation period when it was open to everybody was only, I understand, four to five weeks.

Tim Cooper: I cannot remember the exact length of time.

Baroness Campbell of Surbiton: It was short.

Tim Cooper: We have extended the period, in response to some of those concerns.

Baroness Campbell of Surbiton: For how long?

Tim Cooper: To 25 July.

The Chairman: Thank you very much for your evidence. We would have liked to have asked a few more questions, and we will write to you with them.

Examination of Witnesses

Cynthia Bower [Chief Executive, Care Quality Commission], **Louise Guss** [Director of Governance and Legal Services, CQC], **Hugh Constant** [Practice Development Manager, Social Care Institute for Excellence] and **Don Brand** [Policy Consultant, SCIE].

Q216 The Chairman: For the record, could you introduce yourselves, please?

Cynthia Bower: I am Cynthia Bower. I am the chief executive of the Care Quality Commission.

Louise Guss: I am Louise Guss. I am the Director of Governance and Legal Services at the Care Quality Commission.

Hugh Constant: I am Hugh Constant. I am a Practice Development Manager at the Social Care Institute for Excellence.

Don Brand: And I am Don Brand, a Policy Consultant with the Social Care Institute for Excellence.

Q217 The Chairman: Thank you. Could I ask a general question to SCIE? Thank you for your written evidence, in which you say that “only by understanding what works in practice—and what does not—can services be improved, and the status of the workforce be raised”. What role does SCIE have in promoting independent living for disabled people?

Hugh Constant: SCIE’s general role is to improve the quality of practice in social work and social care by gathering evidence as to what works from a variety of sources from academic research, users and carers, and practice itself, and then disseminating that to the social care workforce. Our role in promoting independent living is to highlight research as to where independent living works well—for instance, the evidence that is mounting about how personalisation can provide independent living for people—and to make sure that those messages get across in a variety of forms to the social care workforce.

Q218 The Chairman: Could you say something about the barriers that you face in this work?

Hugh Constant: In getting the message across, we are always battling to a certain extent against the way things have always been done and some of the historical forms of service delivery. As we try to promote personalised approaches and independent living, the challenge of getting those messages across in the face of how things are being delivered can be difficult.

Don Brand: Can I add to that? There is an issue of scale. We are working in a relatively small organisation to try to improve practice in a workforce of 1.5 million. With you, we want to promote independent living among something like 10 million disabled people, half of whom are over pensionable age. There are issues about how to maximise the impact of the work that we do so that it has most effect among the staff and, through them, to the people using the services.

Q219 The Chairman: What would you say would be the key barriers faced by disabled people in this context?

Don Brand: There is a whole range. There are barriers that they come across in the environment; there are barriers as a result of the way in which services are organised and sometimes not well co-ordinated; there are barriers in obtaining information and in communicating their needs and getting them noticed; and there are barriers, as you have

already heard, in the competition, in effect, between people with needs that they are seeking to have met and the resources available.

Hugh Constant: I would add that another barrier to independent living for disabled people is societal understanding of what constitutes a disabled person. As Don has pointed out, more than half of disabled people are above pensionable age, which is sometimes ignored. People with complex needs such as autism also have a right to independent living, as do people with mental health problems and so on. That broader definition is not yet common in the public domain.

Q220 Baroness Stowell of Beeston: My question is to SCIE as well. I again refer to the written evidence that you have submitted to us. In it you say that “making the right to independent living legally enforceable at an individual level, so that each disabled person has a clear entitlement to independent living and the services required to support it, would build on the body of policy work in a useful way”. Why do you think such additional legislation is necessary?

Don Brand: Our view is that for disabled people, as for everyone else, the more that you can have a say over what happens in your life, and the way in which you live and in which help is provided to you, the better. The issue is how far your say can be strengthened through the right kind of legislation. We are quite encouraged by the recommendations of the Law Commission in its review of adult social care legislation. It seems to be saying, in effect, that people’s entitlements should be stated more strongly; that they should be able to take individual action to support their needs being met; and that the legislation should focus not just on services provided but on the outcomes that people want to achieve. It seems to us that if independent living were to be defined in that list of outcomes, that would be very helpful and supportive to disabled people and the services working with them.

Q221 Baroness Stowell of Beeston: I am interested in that. Do you feel that that is necessary beyond what is already in the UN convention, the Human Rights Act and the Equality Act in terms of what legislation is trying to achieve but is not adequately spelled out?

Don Brand: It is certainly not fully reflected in the legislation as it stands. Some of the earlier answers this afternoon reflected the fact that we have an archaic legislative framework. The step to basing legislation on a right to well-being, which is one of the Law Commission’s proposals, and framing it in terms of the outcomes that people would be entitled to expect and not simply the services that they could hope to achieve, goes several steps beyond what, as I understand it, the UN convention or even the inclusion of the human rights convention in our legislation enabled us to do. It creates an opportunity for the individual and the local authority to engage in discussion with a stronger position for the individual in that discussion.

Q222 Baroness Campbell of Surbiton: I should declare an interest as the founding chair of SCIE. However, all my questions are for the CQC. The role of CQC has recently changed. Could you explain the role that the CQC now has to play in promoting the right to independent living for disabled people?

Cynthia Bower: Our fundamental responsibility is to providers. It is to register providers of health and adult social care against the standards, 16 of which are standards of quality and safety in the Health and Social Care Act. We register providers against those standards and we monitor their ongoing compliance with those standards. We then take action against them if we believe that there is some failure to comply with the law.

The way in which our role has changed is that very early on in our incarnation—we have existed for only just over two years—we had responsibility to comment on the quality of the

commissioning of services, including local authority and NHS commissioning, and to produce an annual statement about the quality of the NHS services through the annual health check, as it was known. But those responsibilities have gone, so our total focus now is on the registration and ongoing compliance monitoring of providers. The legislation under which we operate is very much focused on outcomes for people who use the services and for patients. We have expressed how we will monitor that, in terms of what the experience of a service user should be if the provider is compliant with the law. A number of elements of the law speak to this particular agenda. Outcome 1 is about respecting and involving people who use your service. Outcome 4 is about the care and welfare of people using services. They would cover things like care planning, people's involvement in their care planning and the requirement to promote independence and personalised care, which are intrinsic to those outcomes. That is centrally what our job is in this.

Q223 Baroness Campbell of Surbiton: What do you think the main consequences are of the change in CQC's role with the removal of the regulation of care quality? Could it adversely impact on the right of disabled people to independent living?

Cynthia Bower: The Health and Social Care Act, under which we operate, was constructed to be compliant with human rights legislation. We believe that the rights of patients and service users are written through the Act, and that is intrinsic to the way in which we go about our job. We always try to address the rights of service users in thinking about our regulatory work. More generally, the biggest issue is that we no longer comment on the quality of commissioning. We do not comment on the relative weight that commissioners give to home-based care or on their support for independent living. We merely—I say “merely”, but it is a big job—focus entirely on the providers themselves and not on how services are commissioned.

Q224 Baroness Campbell of Surbiton: It might be too early to tell, but do you think that that has had an adverse impact on independent living?

Cynthia Bower: I think it probably is too early to tell. We ceased doing it only in October last year.

Louise Guss: I would add that in relation to our statutory role—as you know, we are a creature of statute under the Health and Social Care Act—we have very specific responsibilities. The primary responsibility is to register and monitor providers who are registered for specific regulated activities. A provider will come to us and say, “We want to provide personal care or screening and diagnostic services,” and there are 14 of those regulated activities. For example, with regard to home care, we would call domiciliary care agencies, which must comply with the standards that Cynthia has just referred to. Despite the fact that we have become a new organisation and no longer have that role in relation to commissioners of services, we still have a statutory responsibility to apply our methods consistently to the regulation of all services, including domiciliary care.

Q225 Baroness Campbell of Surbiton: That is really helpful. It leads me nicely into my next question, because I want to talk about home care. You will obviously be aware that the recent Equality and Human Rights Commission report on home care found that the basic human rights of older people receiving home care are currently being breached. Do you think that these findings suggest that we should shift our focus away from the right to independent living and on to the prevention of the violation of individual rights, such as the right to be free from inhumane and degrading treatment, including the mistreatment and abuse of disabled people? Do you think that we should stoke that up? We are talking about breaches.

Louise Guss: I understand. CQC's focus is on the providers of the services, and I will say this before I come on to answer the meat of your question, if I may. We look at how the services are provided and check that they are compliant with the standards that we require, as was touched on earlier by Cynthia. The report that is being produced is very important. It has some critical messages about how we as a society support people who live at home. It is very important that we start right at the beginning and ask, "Do we believe that people who live at home and receive services, or indeed live at home independently, should have the fundamental rights conveyed on them by the various conventions and by our own Human Rights Act?" The answer to that has to be, "Yes, of course." I do not think that whether we are focusing too much on independence and not enough on fundamental human rights is a matter for us. From CQC's point of view, we would say that the human rights of anyone using adult social care or healthcare services are fundamental. Our approach to regulation focuses on outcomes for patients or people who are using services, depending on which sector they are in, and we treat each of those outcomes equally in relation to the services that we regulate.

Cynthia Bower: The rights that we think are intrinsic to our approach would be part of our assessment of domiciliary care, as they would with any other sort of care. Having said that, it is important that we acknowledge that it is much harder for us to regulate home-based care than it is, for example, to go into a hospital ward or a nursing home and observe care being given by undertaking unannounced visits, for example. The vast majority of our inspections are unannounced. We have to come up with a different model when we look at domiciliary care. It would be misleading not to point out that it is much harder for us to regulate non-institutional care and home-based models of care. We are looking at how we can get a better understanding of people's experiences of such care, whether it promotes their independence and whether the delivery of personalised care is supported in the way demanded by the legislation that we work under.

Louise Guss: I should have mentioned before that our continuous responsibilities relate to people coming into the market. We deal with the registration of service providers, and we monitor their compliance with the standards and whether they fall below an acceptable level of standards. If, as you identified in your example, we discovered that a provider was falling below acceptable standards or if criminal proceedings were ongoing in relation to any sort of abuse which had taken place and which came to our attention, we would use our enforcement powers to remove that provider from the market. So we have a part to play when information comes to our attention. We have a range of enforcement powers, the most draconian of which is to suspend registration or to cancel registration altogether in relation to the regulated activities that I touched on earlier.

Q226 Baroness Campbell of Surbiton: Have you used that yet?

Cynthia Bower: Yes, we have. We have undertaken enforcement action since we came into existence. We brought the figures in case you asked us and we have them in front of us. The majority of the enforcement action that we have taken has been in relation to adult social care providers, including a number of occasions on which we have either suspended or removed the registration. Equally, there are examples of where we have worked with a provider towards a voluntary closure. That would not come up in our statistics if we believed, and the provider and their commissioners agreed, that the service was no longer meeting standards. So sometimes we will work towards the voluntary closure of a service, as well as taking enforcement action.

Q227 Baroness Stowell of Beeston: This is a quick factual question. You have been at pains to stress that you are regulating only the providers. Who is regulating the commissioners?

Cynthia Bower: With the NHS in future, pending the passing of legislation, it will be through the NHS Commissioning Board. The Health and Social Care Bill going through Parliament will specifically remove our ability to comment on NHS commissioning, so it will be done through the commissioning board. For local authorities, as regards adult social care, although the power has not been removed, the Minister for Care Services made it clear that he wants a peer-led process that the Association of Directors of Adult Social Services and the Local Government Association are working on together. That requirement for us to comment on the quality of commissioning has now ceased. We were asked by the Minister to stop doing that from now on.

Q228 Lord Morris of Handsworth: My question is for representatives of the institute. In your written evidence, I detect a cry for help. You say specifically that “clear delivery structures and sufficient funds would also be of benefit”. Does that mean that you believe these elements are missing from the current delivery mechanisms and available budgets? Can you take us to the evidence you have for this?

Don Brand: If it is a cry for help, it is on behalf of people receiving services and other people who are not receiving them.

Lord Morris of Handsworth: I take that as a given.

Don Brand: In terms of delivery structures, I suppose the example that we would offer links to some of what you have already heard this afternoon. At the individual level it is very difficult to find your way around a system that is complex, in which there are no adequate signposts and where very often people do not know what questions to ask or what powers they have. That complexity is reflected at central government level. We have heard from Mr Cooper about the challenges of trying to achieve a co-ordinated approach across central government. It is inherently difficult to do that. However, because of the problems of central co-ordination—the way that some central policies run into and conflict with other central policies—that then makes for difficulties in achieving a co-ordinated approach locally. It may, ironically, be easier to achieve co-ordination at local level than to wait for the holy grail of wholly joined-up central government. In terms of insufficient funds, there has been plenty of evidence from bodies, such as the recent Dilnot Commission quoting a shortfall figure.

Derek Wanless, when he reviewed adult social care, again gave figures for the extra amount that would be needed. The previous Government put a figure on the gap that they thought was in the system. These macro figures are reflected in the experience that you hear about of individuals whose levels of support are in a number of cases being reduced, apparently as a result of the local authorities needing to find savings. In our evidence, we referred not only to reducing service provision but to increasing charges, particularly for home care, where local authorities have discretion. So there is a great deal of evidence to confirm that the existing resources, even best used, would not be sufficient to meet the objectives.

Q229 Lord Morris of Handsworth: Have you advanced the case to the powers that be for a clearer structure and better funding?

Don Brand: We have done two things in that respect. We have close relationships with the central government departments and with other central organisations, including the Care Quality Commission. Quite a bit of our work is not necessarily making representations but contributing to the thinking and the development work that is going on about how to, for instance, improve the delivery structures. At the same time, the focus of our work, as Hugh said earlier, is on encouraging improved practice at local level. We are supporting the

national social care academy that has been set up to promote more effective leadership and stronger management at all levels in social care. We are working with the College of Social Work that is being established again to support the role of social workers, which is very often to bring together the support that individuals need from a variety of sources. There are a number of things that we are doing and are able to do in our role.

Hugh Constant: To add to that, there is a body of evidence from carers' organisations, including some research that we have done recently, that if you add to the pressure of caring for someone the pressure of navigating through a disjointed system, that can be the straw that breaks the camel's back and makes people decide that they can no longer continue in their caring role. That then adds to the financial pressures because more expensive forms of care are required.

Q230 Lord Dubs: My question is to the CQC. In answer to an earlier question, you talked about some action that you have taken as regards residential home providers. What evidence do you have about the awareness among private residential care providers of the Human Rights Act? Has the recent extension to them of the Act had any impact?

Cynthia Bower: I can answer this only in a fairly tangential way but, of the care providers that we now register, we have looked at about 10% of those—just going through the legislation and the powers that we have. Of that 10% that we have looked at, about 12% were non-compliant on that first outcome, which is about respecting and involving people. About 28% of them were non-compliant on the outcome on care and welfare, and thereby proper planning. Although we do not look at every outcome every time, that is the best measure we have at the moment about how we have looked at those particular things as they relate to our concerns about whether or not the sector is fulfilling its responsibilities on those fundamental rights.

Looking forward, the other thing that we are about to do is work with the Equality and Human Rights Commission on guidance for our staff as regards looking at how the equalities and human rights legislation impacts on our own work, and how, when our inspectors go in, they can think through the outcomes that it is looking at in terms of equalities and human rights legislation—for example, what to do if the inspectors believe that a provider is in breach of people's human rights and where they can go with that information.

We are trying to increase the awareness within our own staff of equalities and human rights legislation. At the same time, in looking at those basic outcomes for service users, we are fundamentally looking at human rights. As I say, we are seeing numbers of providers who we think are not necessarily respecting basic rights. We have also completed some work in the NHS. I know that it is a different issue but we have carried out 100 inspections in hospitals, looking at dignity and nutrition. Again, we found that about 10% of providers were not compliant with those fundamental rights.

Q231 Lord Dubs: Could I ask a supplementary to that? You have clearly showed what you are doing to increase awareness. Do you think that the Government should be doing more?

Louise Guss: I think the work, for example, of this Committee in highlighting the gaps, where they exist, and in highlighting the areas where we need to work harder, is essential so that the Government can understand the opinions of not only stakeholder organisations that work in this field but also individuals and disabled people who are receiving services. My view is that you can never say too much. We constantly need to remind ourselves, as a society, of the rights of people who are in receipt of social care and the people who are living at home in receipt of social care. As to the question, "Has the Government been doing enough?" I do not think that I am in a position to answer. There can never be enough

promotion, in my view, of the human rights of people who use social care and health services.

The Chairman: You will appreciate that we are not the Government. We are a Joint Committee of Parliament. Thank you very much for your answers today. We would have liked to have asked a few more questions, but we will write to you with them. As I have said to previous witnesses, if those supplementary questions do not cover all the ground that you wish to cover with us, please send us a memorandum. Thank you very much.

Rt Hon Grant Shapps, Paul Burstow and Maria Miller
Oral Evidence 25 October 2011, Q 231–277

EVIDENCE SESSION NO. 6. HEARD IN PUBLIC

Members present:

Dr Hywel Francis (Chair)
Baroness Berridge
Lord Bowness
Baroness Campbell of Surbiton
Rehman Chishti
Lord Dubs
Lord Morris of Handsworth
Virendra Sharma

Examination of Witnesses

Rt Hon Grant Shapps, [Minister of State for Housing and Local Government, Department for Communities and Local Government], **Paul Burstow**, [Minister of State, Department of Health] and **Maria Miller**, [Minister for Disabled People and Parliamentary Under-Secretary of State, Department for Work and Pensions]

Chair: Good afternoon and welcome to the Joint Committee on Human Rights. This is an important session, because it is the last evidence session on our inquiry into independent living. That is not to say that you have the last word, with all due respect, because obviously we have to write a report in due course. For the record, could you please introduce yourselves?

Grant Shapps: I am Grant Shapps. I am the Minister for Housing and Local Government.

Maria Miller: I am Maria Miller. I am Minister for Disabled People, and I am a Minister in the Department for Work and Pensions.

Paul Burstow: I am Paul Burstow. I am a Minister in the Department of Health. I am the Minister for Care Services: I cover health and social care in that brief.

Chair: We will begin with some general questions on “joined-up government”, and the particular legal obligations under Article 19.

Q232 Baroness Campbell of Surbiton: The Chair has kindly let me kick off this session. I am very pleased to see all three Ministers, and to have the opportunity to have all three Ministers in one room at one time, which sets a good spirit across Government. I will kick off with a couple of questions to all three of you. What in your view is the nature of the legal obligations contained in Article 19 of the Convention on the Rights of Persons with Disabilities? Does the Government regard Article 19 as hard law or soft law?

Maria Miller: I thank the Committee for inviting us here today to talk about the work the Government is doing across all Departments in this area. Baroness Campbell, starting with issues around Article 19, gets to the heart of the matter straight away, and I should not expect anything different from her. It is absolutely right that all of the work that she was involved in with regard to the independent living strategy and the importance of independent

living is at the heart of everything that we are doing as a Government. I will leave my colleagues to talk about how that affects them in their own Departments. The work we are doing with the Disabilities Strategy will have issues around independent living, and many other issues within the UN Convention, at the heart of how we move forward.

Is it hard law or soft law? As I am sure the Baroness is aware, the UN Convention is soft law—if one uses those terms—because it is a Convention that does not have legal standing, but it is very much a Convention which every Department is signed up to. The work that I have been doing concerning the reporting around the UN Convention shows that awareness of the issues within the Convention is very top of mind. If Baroness Campbell wants a more informal feedback, it does drive at the heart of our approach although technically, as she rightly shows, it is a soft law approach.

Q233 Baroness Campbell of Surbiton: Article 4.1.c of the Convention requires states to take account of the impact on disabled people: you have that obligation. Can you describe how the Government assesses the impact of policy proposals on the right to independent living?

Maria Miller: To kick off that as well, the issue of independent living is at the heart of what we are trying to do as a Government. Therefore, when we undertake an impact assessment, as we have done on things like housing benefits through the Welfare Reform Bill, the ability of those policies to be able to deliver behind that premise is inherent within our impact assessment.

Paul Burstow: Can I add one or two things? Last year the Department of Health commissioned some work from Radar to work through the impacts that the Convention would have, and to put it in the context of the statutory framework—the duties that exist in law already. They published some basic conclusions in terms of how the Department of Health should approach this, which said to us that we needed to ensure we were strengthening commitments around promoting independent living and that we were improving integration, which, I know, has been an area that you have looked at as part of this inquiry.

Quite challengingly, and rightly, they raised with us concerns about the need to address the perceived hierarchy of impairments, that there needed—this is my way of putting it—to be a parity of esteem between physical health issues and physical disabilities, and mental disabilities, mental health issues, and learning disabilities. We are now working that through in the context of the health reforms, and the forthcoming social care reforms.

Q234 Baroness Campbell of Surbiton: Mr Shapps, I do not want to leave you out—are there impact assessments under the Convention?

Grant Shapps: I was going to add in any case that local government is at the heart of needing to deliver the commitments under the Convention, and that takes a lot of different forms—the Equalities Act is an obvious example—even through developing policies such as local health boards. I know through my work with local authorities it is typically at the forefront of their minds, and it is right that it should be so: they have to provide due regard to equalities at all stages of their policy development. It is embedded in the work that they do. But you asked a question on a specific aspect—the impact assessments.

Q235 Baroness Campbell of Surbiton: Are there any impact assessments that you are aware of that are live within your particular Department?

Grant Shapps: In local government, an impact assessment automatically has to take these issues into account, and quite rightly so. It is my intention as Local Government Minister to make sure they adhere to that, and I will do everything I can to ensure it continues.

Q236 Baroness Campbell of Surbiton: What assessment of the impact on independent living was carried out, for instance, by the Government for the recent budget cuts—a very important one? I would like you to be a little more detailed if you could. Who would like to start?

Maria Miller: I can kick off on that. We published a full impact assessment in April 2011 around the housing benefit changes, which is one of the current issues that you are considering with regard to some of the changes we have been making to welfare reform. That included the impact on disabled people. The way we considered the Article 19 requirements in terms of independent living was part of that full impact assessment. It was clear from the impact assessment that there was impact across the board on people, but that that did not disadvantage any particular group. We need to do things to manage Housing Benefit expenditure, and that is really important, but even after the changes that we have made around 30% of housing² is still available to individuals who are looking to rent in the private rented sector.

More importantly, we have had that impact assessment looked at, at a judicial level, and it was found to be a very fair and correct way of assessing the needs as part of that impact assessment. That is an example of how we have taken forward an impact assessment to ensure we are doing what we need to, to underpin independent living.

Grant Shapps: The argument is won out there in the country that it is crazy to be paying nearly £50 billion in interest on servicing a debt each year, and that something needed to be done; reducing the deficit has been this country's way of addressing that issue. You asked a question about what the considerations were in making these budgetary changes. In my area, for example, Supporting People, which is a budget I look after, remains at £6.5 billion throughout the four years of the Spending Review period. Whereas other budgets were taking cuts of a quarter, or even a half in some cases, Supporting People has less than a 1% reduction in the budget in cash terms each of the four years, so it is largely protected.

In addition, things like the Disabled Facilities Grant, which I can reveal I fought hard for, is my only budgetary line that goes up in expenditure over the period of the Spending Review, from £169 million to £185 million per annum. We can say we want to protect the most vulnerable until the cows come home, but unless you put some meat on the bones, explain what that means and do something about it then it does not have much meaning. That is why I was keen to ensure the Disabled Facilities Grant increased.

Paul Burstow: I will touch on a couple of aspects of that—first, perhaps, the NHS. It is important to set the NHS in its broader context, not just the Spending Review. Back in 2009 the Chief Executive of the NHS set an efficiency challenge for the NHS of identifying between £15 billion and £20 billion of savings, effectively over the life of this Parliament. When the new Government came in, we took a view that that programme, which had been initiated, needed to carry on; to look at how we could improve quality; to look at how we could improve productivity; but also to focus on prevention and innovation in the way in which services are designed. That programme requires central Government to have a role to play in providing support, but a lot of the decision-making, and thus the exercise by decision makers of their duty to have regard for their equality duty, will sit with local decision makers.

One of the things that we are reinforcing through the equality delivery system that the NHS is now rolling out is that that is always in the forefront of decision makers' minds when they

² Note by Witness: Outside of Central London

are making decisions about budgets. In terms of social care, we had an extensive debate about the impacts of inadequate funding of social care; I suspect that will be an area we will drill into more during this session. What we established at the beginning through the Spending Review was that we needed to provide additional resources: there is a £7.2 billion over the life of this Parliament going into social care, and that was driven, not by a separate impact assessment, but by it being an integral part of the ongoing dialogue between Treasury and DH as we came to the Spending Review settlement.

Q237 Lord Dubs: Mr Shapps, you talked about the budget, but you did not allow for inflation in all of that; you talked about it in cash terms. If inflation stays at 5% then these represent quite important cuts, do they not?

Grant Shapps: I do not want to pretend that there was a lot of money swishing around and we were able to do incredible things. What I am trying to point out to the Committee is that the same inflation point will work against all budgets across government—housing, for instance. In relative terms, rather than being reduced by half, which my housing budget was, these were budgets that we fought for, largely maintained, and, in one case at least, increased.

Q238 Chair: Some of the witnesses who have appeared before us have indicated that they were concerned about what appeared to be a lack of sufficient communication within government, and between this Government and devolved administrations and local authorities, regarding the importance of implementing the UN Convention. Could you outline to us what you are doing in this context: what are the barriers to taking a cross-government approach to implementing independent living, and how are each of your Departments trying to tackle these barriers?

Maria Miller: I will start on that, Mr Francis. It is not for Westminster to determine how devolved governments respond to areas that they have responsibility for, but you should be assured that we share good practice and routinely consult on policy changes. Indeed, in the last month I have been up in Scotland meeting the Deputy First Minister, and have regular conversations with my counterparts in the devolved administrations. There are some very good examples of how we work together across the devolved organisations, even in areas like DWP where we have benefit and employment policies that are not devolved: we still work together on areas where we can join up our policy. In Northern Ireland there is a Disablement Advisory Service, which works on vocational programmes locally. In Scotland there are various programmes like Workforce Plus and Scotland's Supported Employment Framework. In Wales there are programmes like Want to Work, and joint working between Jobcentre Plus and the Welsh Assembly.

There are areas of work on the ground, and it is important that we join those up, even where we have national responsibility. At the risk of straying into areas that are not my own departmental responsibility, but in which I have an interest as Minister for Disabled People, the Government has done a good job of coming together to tackle hate crime, an Article 16 issue. We have a UK-wide commitment on tackling hate crime: we for the first time put in place a regular reporting mechanism for the police; also, England, Wales and Northern Ireland work together on trying to help people understand new ways of reporting hate crime. That was very much working across the devolved administrations to try and get maximum benefit for disabled people. The work we have been doing around the UN Convention reporting also has enabled us to work closely with our devolved partners on the work they are doing now.

Q239 Chair: The focus of my question should have been more specifically on cross-governmental communication; I apologise. While it is important to have some kind of communication with the devolved administrations and local government, the concerns of witnesses who previously appeared before us was mainly about inter-departmental relations within this Government

Maria Miller: The difficulties of trying to work across government are inherent in Government. It is something that every Government grapples with. The structures we have in place through instruments like the Cabinet Sub-Committee on Social Justice and the Inter-Ministerial Group on Equalities mean that we have some very firm structures with extremely good leadership, which can take up the issues that affect disabled people on a cross-government basis. Having those structures in place is vital in getting the sort of joined-up working you are talking about.

Grant Shapps: That has not been my experience as a Government Minister for the last year and a half. I imagine that some of your witnesses may have been thinking of communication between DCLG and DWP when it comes to things like the housing benefit changes, which are obviously DWP-led, but have a big impact on my areas, my budgets, and the people who I am trying to help. I am 100% signed up to the overall Government objective that DWP is the Department that is responsible for pressing in this regard, which is that we must get to a system where work pays, for example. If you believe that, then you have to have the universal credit; and if you believe that then there have to be changes to the way that housing benefit is delivered; and if you believe that, then you have to be prepared to work as a Government, and cross-departmentally, to do it.

In my view it would be impossible for the DWP to have reached this position with the universal credit had we not worked very closely. We will fight our corners; I am very blunt in a private meeting with my opposite numbers. Nonetheless I sufficiently subscribe to the overall objective. It is almost the other way: the working is quite efficient behind the scenes, the officials work very closely together, and, talking to officials in the Departments, they will say that it compares favourably to the way that Governments have operated in the past.

Q240 Chair: I think that the witnesses were more concerned about what you said then: your starting point is, “If you believe that work pays”, but they would probably answer that by saying, “Our starting point should be a respect for independent living, and recognising and working towards that”.

Grant Shapps: I will give you one simple example of exactly your point. If you want people to be able to live and work independently, and you need a seamless transition where people are able to come into work, then there is a policy that could potentially cause a difficulty between our two Departments, on direct payments to individuals rather than to landlords. However, it is an area of policy where we have worked incredibly closely together, understanding our respective objectives, compromising, discussing, working through the detail, and doing it carefully and constructively, for example if we are setting up pilots that would be meaningful in the outcome and the way this will operate. That is a very good example of the Departments working closely.

Maria Miller: At the risk of cutting off my colleague, I will give another example. The Right to Control pilots were a great example of taking a policy that was developed under the previous administration, but under the new administration we took that forward, working with the Department of Health and with my colleagues in local government. The reason the Trailblazers are working so well is because of that cross-Government working. When I go out to the Trailblazer areas, that is the message that I receive back from people who are on the ground.

Grant Shapps: The fact that all three of us are here is a good indication that we work well.

Paul Burstow: I want to add one other example of where that has been essential to deliver Government policy priorities, which is in the work that has been done across Government to produce a life-course approach to delivery of mental health, with our mental health strategy No Health Without Mental Health. That has not only had cross-Government buy-into it, which is essential to its delivery, but also a lot of collaboration across government to ensure the delivery is not just seen as a Health delivery for mental health, but one requiring engagement, policy work from DWP, colleagues in DCLG and other Government Departments as well. That was done very early in the life of this Government, and is a measure of the fact that there is good architecture in Government for those cross-departmental discussions.

Q241 Chair: Mr Shapps, I appreciate the fact that you are all here, but you are all here because we invited you here. Without labouring the point, I take it you acknowledge that this question of communications is a challenge?

Grant Shapps: Absolutely, without a doubt. As you say, we are all here because you invited us here, but the Committee commented initially that it was good to have everyone here, which is the only reason I raise it. It is very easy from the outside for people to imagine a silo situation, which, in many cases, and certainly in my experience from the last year and a half, has not existed at all. I cannot think of a single issue on which I have not been able to pick up the phone, call another Minister, write with officials, and get that problem fixed—not one where we have not come to a solution. There is a wider shared objective among Ministers to attempt to be both protecting the most vulnerable, and fix this enormous global problem of budget deficit. We work on it very determinedly and could not have made this progress if we had not worked together.

Q242 Mike Crockart: At the risk of going back down the route we started to go down with the previous question, obviously there is a difficulty in the devolved responsibilities: we have the problem of delivery being the responsibility of some devolved institutions, whereas the responsibility for implementation of the UN Convention still rests with the UK Government. Since you have given a fairly extensive answer already, could you, Mr Burstow and Mr Shapps, talk us through your experience of your dealings with the devolved Governments? If you can thread in a few examples as well it will save me coming back with my supplementary.

Paul Burstow: I will kick off by framing it partly in the context of the Department of Health's relationship with local government, which is one area where there is devolution.

Q243 Mike Crockart: That is my next question

Paul Burstow: In that case I will not start with that; I will let you ask that in a moment. In terms of our day-to-day engagement with colleagues in devolved administrations, the Department of Health does not presume to tell other Governments within the UK how they should be discharging their duties in terms of the Convention. That would be a presumption that Parliament should frown upon, given that we have devolved those competencies from this place to those places. We have a constructive engagement around policy development, we are interested in areas where they are developing policy that might inform our policy developments, and vice versa.

But in the context of our reform agenda, the approach that we are taking as a Government is one of saying that we want to push power and decision-making towards the front line, that we want to see service users/citizens not just in control of the way in which services are designed, but also in control of the services that they themselves need to support their independent living.

In that context local government has a key role to play as an agency for enabling that to happen. Regarding the healthcare reforms that are going through Parliament currently, one of the key elements in the reform structure, which will further facilitate that and help bring together a number of the agencies that have the equalities duty placed upon them, and have to deliver around this agenda of independent living, is the existence of health and well-being boards within local authorities. Those boards bring together health, social care, (both children's and adults), directors of public health, and elected members of those authorities to assess need for their populations, but also set strategy for the way in which services are commissioned and shaped. They are all being placed under duties to involve service users right from the outset, and throughout that process.

One of the lessons that we are drawing as a Government is that, even under constrained financial times, the places that are doing best are the places that are involving most; the places that are damaging people the most are the places that are ignoring people the most. That has been a lesson for us as a Government; it is a lesson that local government is also learning.

Grant Shapps: I echo many of those comments: my roles as Housing Minister and as Local Government Minister are both England-only roles. I suspect the thrust of your question is not really for me, except to say that my experience has been very similar to that described by Paul when it comes to developing new policies. I am about to launch the first ever nationwide ability to swap a social home, literally being able to see the entire picture right the way across the UK. This would apply to people who may have homes which have been adapted and want to swap homes. I have had excellent co-operation, regardless of parties and control, from the devolved administrations, and I meet with them regularly, so if any of these issues are coming up they can always be raised. It is not the case that I have the power, authority, and control over the way local authorities and, for example, Scotland deliver this particular duty.

Q244 Mike Crockart: Your answers concentrated more on local authorities, and that was my next question. We have had evidence from a number of people who have talked about the differences in emphasis and focus not only between the devolved responsibilities, but, even within those devolved Governments, about the differences between many local authorities in terms of how they deliver services, which are such that it has stopped them being able to move between different local authorities. You say that those that are ignoring the people most are those that are damaging them the most: do you see that there is currently a correct division of responsibilities between central Government and local authorities to ensure that someone has ability to step in and make sure that that is not happening?

Paul Burstow: There are several different aspects there: there is an aspect around how you drive improvement and where the responsibility should sit, first and foremost, for that, and then there are some questions about portability. In terms of the overarching responsibility, of course decision-makers in local authorities, when they are making budget decisions, when they are making decisions about service design and so on, are very clearly under the equalities duties. They have to have regard for those things clearly set out in statute in terms of how they make their decisions, and they have to be able to evidence that.

Those that cannot evidence it fall foul of the law and ultimately judicial review as well. That itself is a very helpful corrective, because local authorities are very sensitive to the outcomes of judicial reviews and change their practice accordingly. It has that impact as well. When it comes to the approach that the Department of Health has taken to improvement, particularly in the context of social care, since the election is one of developing sector-led improvement. We have an agreement of understanding between ourselves and the Local

Government Group around how they have, in the first instance, the responsibility of providing both peer review, peer challenge, and peer support for those authorities that, for one reason or another, are not performing amongst the best when it comes to delivery of social care outcomes.

That programme is still in its early stages and a lot of work is being taken forward. I was at the National Children and Adult Social Care Conference last week where I was getting very encouraging feedback among the directors of social services for the work they are doing in that regard. We have retained as a backstop the ability for the CQC to conduct inspections of local authorities and so on if necessary, but we want to enable the sector to take much more responsibility for driving up quality itself.

The issues of being able to move from one locality to another is at the heart of a number of the recommendations that the Law Commission has made in its report published in May of this year, and Baroness Campbell currently has a Bill in the Lords about portability. We are looking closely at that. When we set out our vision of reform of adult social care last November, we indicated that it is an area we think has to be addressed. My view is that it is a vestige of the old poor law principles, from which we need to get away in the 21st century, and we will be coming forward with a White Paper next year, which will set out precisely how we intend to do that.

Grant Shapps: I have three comments on local authorities and the way they undertake this, and a suggestion. Local authorities have a legal duty under the Equality Act, which they should therefore be undertaking. In my experience, local authorities by and large are very conscientious about trying to adhere to legislation. There are two additional checks: they are accountable in the way that few quangos are, inasmuch as they have elections and have to account to their electorate, and there is recourse to complaint through the Ombudsman and/or eventually judicial review, two steps they are very likely to take account of.

Sensing what you are saying here—the question about how this is ensured across the board and perhaps the portability issues that have also been raised—I would be happy to have a conversation with the Local Government Association about whether this is something they could do more on to ensure the UN Convention is being fully taken into account. Perhaps I will undertake to the Committee to go away and have that conversation.

Q245 Mr Sharma: The Office for Disability Issues and Breakthrough UK have both told us that valuable lessons have been learned from the Right to Control Trailblazers in terms of joining up across different policy areas. Could you tell us what lesson you think each of your Departments has learned, and what implications this might have for future policy implementation and delivery?

Maria Miller: First, I would pay tribute to all of the people I meet out around the seven Trailblazer areas for the work they are doing to make those Trailblazers work: some of them are quite large areas. I was in Manchester talking to some of the people who are delivering there, and I think we owe them a debt of gratitude. It may be a little early in the process to draw too many lessons learned because the last trailblazer only went live in April 2011, and we are therefore still in the early stages of testing the seven Trailblazers across England. There will be an interim evaluation next year and a final report in 2013.

I will stick my neck out and say that there are a couple of things that we have learnt already. The first is that co-production with disabled people, right from the beginning, has been a very successful part of this whole process, from policy development through to implementation. I was in Yorkshire in the summer, meeting some of the people who were participants in the Trailblazers there. The other lesson I would draw from meeting them is how empowering the process is, being able to take the funding streams available and use

them in innovative ways. I felt that the sense of choice and control among the disabled people I met was already a lesson learned, although we are in the early stages.

Grant Shapps: I do not have too much to add to those points about the Trailblazers. Both Supporting People and Disabled Facilities Grants are included in this. It is a good example, Mr Francis, of where we have been working closely as a Department: Supporting People is a DCLG budget; DWP has been working on the Trailblazers; so we have been working closely together. There has been some concern about the level of take-up, because it only applied to newcomers, but we are reaching the point where we may be able to retrospectively include people already in receipt of support. Other than that I endorse everything that has been said.

Paul Burstow: The experience we have had over a longer period of time, with the rollout of personal budgets and direct payments in social care, and more latterly the work that is being undertaken around personal health budgets, is of the notion of co-production being at the heart of it. Promoting a sense of personal autonomy is a key part of the way in which this works. The budgets themselves are a means: the end is greater personalisation and greater control. That ethos challenges some professional barriers; it takes time to redesign the way in which services work, but from the evidence we have seen from the health pilots and over a number of years in social care, it is an overwhelming case that that is a model for delivering what people need in terms of outcomes, not just in terms of services for the future.

Chair: Most of the following questions are addressed to particular Ministers: Mr Sharma's question is to the DWP Minister.

Q246 Mr Sharma: The Australian Government has followed up its submission of an initial report to the UN CRPD Committee with a national action plan to implement the Convention in accordance with their international standards and best practice. The UK Government's draft initial report hinted that the forthcoming Disability Strategy would serve a similar purpose. Is this the case? If so, how have the Articles of the UN CRPD informed the strategy? Will the strategy address all aspects of the Convention?

Maria Miller: Yes, the new Disability Strategy will take the UN Convention as its basis and focus on priority areas that are identified by disabled people. I am not going to sit here and say what all those areas are, because we are still in the initial stages of talking to disabled people and organisations about it. Our vision is clear: we want to remove barriers to create opportunities for disabled people to be able to fulfil their potential and be fully participating members of society, very much building on the Independent Living Strategy.

What articles have informed the strategy? There are three areas that I would take generally: how we increase individual control; how we ensure that our aspirations are realised; and how we ensure a change in attitudes and behaviours. We are going to look at those three guiding lights across the work of government.

You asked particularly whether the strategy will address all aspects of the Convention: we have only just started an intensive period of collaborative working—it is collaborative working rather than consultation—with disabled people, which will result in the publication of a strategy next spring. The strategy will include a clear action plan for implementation. The plan will be formally finished towards the end of next year.³ That whole approach is the right way to take things forward, using the UN Convention as a starting point.

³ Note by Witness: 2012

Chair: We now move to questions involving disabled people and their organisations specifically.

Q247 Baroness Campbell of Surbiton: We are all very aware that there has been a great deal said and done since 2005, and the very detailed cross-government strategy, Improving the Life Chances of Disabled People. Mr Burstow clearly said that involving disabled people, co-producing with disabled people, is the recipe to good services and good policy. Can you tell me what outcomes you hope to achieve from the strengthening of disabled people’s user-led organisations programme? I would like to know, simply, what steps are being taken to involve disabled people and our organisations in the monitoring and implementation of the UN Convention. What obstacles to this progress do you see there might be?

Maria Miller: It struck me very quickly that, if we are going to be as successful as we want to be in terms of independent living, we need to be able to support disabled people from the grass roots. Strengthening the voice of disabled people in their communities is a critical part of this whole process. The aim of the programme that we have put in place to strengthen user-led organisations is to ensure that we have a national network representing the views of disabled people in place by 2013. It is a critical part of ensuring we have a strong way of disabled people voicing their views on a local level, but also user-led organisations becoming providers of local services.

Some of the best organisations that I have visited in various parts of the country are those that have tackled some of the real needs of disabled people in their local community; I am thinking of the Essex Coalition of Disabled People and the work they do, particularly in service provision as well as other areas like advocacy, but also those in Sussex and Manchester. There are many areas that have strong user-led organisations, but there are other areas where there is a vacuum. The objective of the programme we have put in place is to fill those vacuums with the expertise of those who have got successful organisations under their belts.

We want to ensure that we have clear oversight of how this is progressing; we have established a steering group of independent experts to oversee the progress of the programme and to ensure that we remain on track with the work that we are doing. Our objective is very simple: we want these organisations to be able to provide that strong voice and ensure they can build capacity for bidding for government contracts into the future. That is the premise behind the work we are doing.

Q248 Baroness Campbell of Surbiton: There has been a great deal of rhetoric in this area, in addition to the work the Department of Health has done in the development of user-led organisations—a strong user-led organisation in every location—and on the design of centres for independent living. However, what we are receiving more than we anticipated is the feeling from people who came to give evidence, disabled people, that there was no meaningful involvement of their voice in the development, implementation and monitoring of policies that affect their lives. We hear a lot that “We are going to have this programme, there are some good things going on,” but there is a significant rise in the number of disabled people, through the evidence sessions, saying they did not feel they were being meaningfully involved. Can you explain that and the obstacles to that? What do you see as the disconnect between the two?

Maria Miller: There are two issues there. You spoke about whether or not people feel that their input into the whole process is meaningful. We have given examples already of where disabled people’s input into the process has been demonstrably important, Right to Control being one, and the user-led organisations being another. They have shaped not just the

project itself, but the need for the project, which came from disabled people and disabled people's organisations.

Q249 Baroness Campbell of Surbiton: Disabled people said the Right to Control had been a very good example, but they felt that in recent years this was going off the boil, and were very worried about involvement.

Maria Miller: The involvement there is absolutely clear, whether it is through Equality 2025, the immense consultations we do on things like the reform of the Disability Living Allowance—we had some 5,000 taking part in that—or the formal work that I do on a daily basis, meeting with disability organisations. I do not think there is an issue with having that conversation, but it is important that people are able to see how that influences the way forward in that policy area.

I take the Personal Independence Payment as a strong example of how that work—the consultation and meetings—is demonstrably influencing policy. We are going to be publishing revised assessment criteria for the Personal Independence Payment that directly address some of the issues that disabled people have raised. If I look at the work that Professor Harrington is doing with disabled people and disabled people's organisations around the assessment criteria for the Work Capability Assessment, again, there is demonstrable input, which is being taken into account as we move forward that particular area of work.

Is it that people feel they are finding it difficult to be always listened to because we do not always completely agree on every single area? I think that may be some of it. Certainly we are listening very strongly, and taking into account issues that are raised when we are able to. There is always going to be a need for us to work together and understand there will be a very proactive and important tension between the two groups.

Chair: We are keen to make progress. We will undertake to ask shorter questions, if you undertake to give shorter answers.

Q250 Lord Bowness: My question has already been put, but could we have the answer from Mr Burstow? The user-led organisations have been identified by the Health Department as having an important role to play in the transformation of social care. The question is: what is the Health Department doing to ensure that it can fulfil that role in the context of the evidence we have had from organisations that are receiving cuts in funding from the local authorities? It has been put to us that it does not experience a level playing field in the context of tendering for local authority services. I ask particularly what the Department of Health's comment might be.

Paul Burstow: There are two or three aspects to that. The Department of Health has had a programme of funding of the initial capacity building around ULOs over the last few years. The funding of that was always going to come to an end; it was always about building capacity and self-sustaining organisations. As you have just heard from Maria, that programme is carrying on in a new way, because we recognise that there are still gaps in the presence of ULOs around the country that need to be filled.

Since then, the Department of Health has worked with colleagues at the Association of Directors of Adult Social Services and the LGA to refresh a piece of joint protocol work that exists around the development of centres for independent living, concerning the role that user-led organisations can play in the provision of direct payments services. We are trying to ensure that local authorities see them as a partner of choice when it comes to providing brokerage and advice services and so on. That is part of the ongoing reason why we are investing in and supporting them.

At the centre of this must be: what outcomes we are getting from the investments we are making; what outcomes we are getting that materially affect people's quality of life and advance the agenda around independent living? I would offer two things as evidence in that respect. One is a report published by In Control in May, looking at the outcomes of the national personal budget survey. It concluded that in the areas where people are directly involved in designing the package of services, identifying the outcomes they want to achieve from their personal budgets, the level of satisfaction with that budget and what it achieves is very high. Similarly, we know from some work that Scope and Demos published earlier this year that when it comes to local authorities making tough decisions about the budgets they have to set, it is not a straight line between the biggest level of overall reduction and the impacts on the front line. That is because some local authorities are looking at how they can integrate services more effectively; they are being innovative in their relationships with the voluntary sector; and they are looking to foster independence and not dependence. That shift in the model means that the resources can be used better.

Q251 Lord Bowness: On a narrow point, in the context of tendering, do have we any evidence of numbers of organisations that have been successful in tendering?

Paul Burstow: I do not have the figures to hand. I can make some inquiries and provide an additional note to the Committee if that would be of help.

Q252 Lord Morris of Handsworth: Mr Shapps, your colleague told us about and you have confirmed the impact that disabled people's organisations have had on policy-making. It is important for us to have a view on whether it is the individual or the organisation that has been involved. We would like you to give us your views about housing policy and to say whether you have involved the disabled people's organisation or the individuals in the development of your housing policy.

Grant Shapps: Very much so, is the answer. It is a pleasure to have the chance to talk about some of these things. Internally, we have something called the housing sounding board; we get together with my most senior housing officials and invite people in to test out very early-doors ideas, before they have been fully developed. We recently invited Sue Adams, of Care & Repair England and chair of the Housing and Ageing Alliance, to join that sounding board. That was very useful indeed and, to answer your question, involves both individuals and organisations; the Housing and Ageing Alliance represents a large number of organisations covering a range of groups—Care and Repair England, the Chartered Institute of Housing, Counsel and Care, the Elderly Accommodation Council.

Through that, we try to sound out policies before they have even been developed. We are trying to embed the idea that we involve the work of organisations and individuals who can advise on disability before we even formulate something into a real-life policy that we might, for instance, send for Whitehall clearance through the Home Affairs Committee. This is a very ground-floor discussion with organisations to try to push us in the right direction.

Q253 Lord Morris of Handsworth: You obviously have access to them, but do they have access to you?

Grant Shapps: That is a very good question. I hope that is a two-way process. I can provide a list to the Committee of the organisations who take part. Some of them in themselves represent thousands of different bodies and organisations; for example, the National Housing Federation will represent 1,200 individual organisations, some of whom will have particular interest in the subject, but not all—or not all as much as they should, probably. The answer is that we do, but I would be interested to hear feedback in the other direction if we are not.

Q254 Lord Morris of Handsworth: When you have consulted and reached a view about policy, before implementation, do you advise them?

Grant Shapps: As I said, they have been instrumental in the way we create the policy in the first place. There is another step that I should mention. Take the national planning policy framework; it has just been out to consultation, and we have had 13,000 responses, but my officials will go out of their way to ensure that we get representation from organisations that are clearly important to these types of strategies. I know that in the case of the NPPF, Andrew Shipley's organisation's views will have been sought within that process—he is formerly of the Disability Rights Commission and chair of the UK Institute of Inclusive Design. If we have 13,000 different organisations responding, my eye is always on ensuring that those that might represent the interests of those with disabilities are being inclusively engaged in the process.

Maria Miller: I have one very short supplementary point. The DWP involves housing groups and welfare groups in such things as the drawing up of the discretionary housing payment guidance, so they are practically involved throughout the policy process.

Q255 Baroness Berridge: Housing is an important part of delivering disabled people's Article 19 rights. The Committee has heard from witnesses such as the United Kingdom Disabled People's Council and the College of Occupational Therapists, and they express concern that disabled people are facing major barriers in achieving housing suitable to their needs. Specifically, what housing policies are there, or will there be, that will contribute to delivering suitable housing under Article 19 obligations? Can you give examples of specific policies that will increase the access to suitable housing for disabled adults and children?

Grant Shapps: Let me try and do that by listing a number of areas. The disabled facilities grant that we touched on at the beginning received an increase in budget, uniquely among all my budgets. Handyperson, which is £51 million, is a very good scheme that practically helps people to remain in their homes with small-scale applications. Supporting People's massive £6.5 billion budget is not subject to the same kind of reductions, although there are clearly issues on the ground about how the money is spent. People often wrongly say about Supporting People, "Why did you un-ring fence it?" I did not; I was not around in 2009 to do that. It has been un-ring fenced for a while. It is a concern to me to see how it is spent on the ground. None the less, from a government perspective, £6.5 billion has gone into it. The FirstStop Scheme is an important place for people to go to get advocacy on these issues.

You asked about the delivery of some of these policies. I recently announced that we were going to be able to increase the number of affordable rent homes that we will deliver between now and 2015, and, of those homes, 9.5% will be for people in supported housing—old people, vulnerable people or disabled people, including children. Under Boris's London plan, 10% of that housing will be wheelchair accessible. I hope you can see through this that there is a theme.

We also have a scheme called HOLD, which has been running for some time. It has helped something like 533 families go to the private sector and find a suitable home and have a local authority and a registered social landlord partner in order for them to buy the house through a shared equity arrangement.

Finally—because I want to keep this short—we use a range of codes and standards through housing policy to try to deliver appropriate housing—the Code for Sustainable Homes, Lifetime Homes, Secured by Design, Building for Life, Home Health, Wellbeing, and several others, some of which have other objectives as well. There is a theme running through policies to try to create housing that is appropriate to the population.

Q256 Baroness Berridge: You mentioned specifically the Handyperson scheme, but the Committee has received evidence that not just the lack of accessible housing but the delays in getting adaptations done are resulting in disabled and older people staying in hospital longer than necessary—Mr Burstow might not be happy to learn this—and/or being discharged into residential nursing homes against their wishes. What more do you think needs to be done through housing policy and investment to prevent that kind of situation?

Grant Shapps: As a constituency MP I have been endlessly frustrated by exactly this point. Frankly, the stupidity of having somebody in hospital, normally at enormous cost to the relevant department, and not being able to get the fixes at home done to get them out, is crazy. It is one of the reason for the health reforms, which Paul can speak to better than I, that join together local authorities in the provision of health in a good cross-working approach that has not been taken before.

There are absolute maximums for decisions in writing within six months, but if the proposition that this is far too long is being presented to the Committee, I completely agree. As a constituency MP I have fought those types of cases. I have invited the Home Adaptations Consortium to publish a good practice guide. It has not been announced yet, but I can tell you up front that it is coming forward. We look to learn from the best examples. The home improvement agencies in some places, Bristol for example, have been doing great work, and, as with all these things, if we could convince everybody to do as well as the best, or even half as well as the best, we would probably see dramatic advances. It might be interesting to get a health take on this as well.

Paul Burstow: I would underscore the point about some of the reforms we are making around health at the moment which—for the first time—give local authorities an opportunity to look at how we commission services in a much more joined-up way between health, social care, and indeed housing, to ensure that those budgets are used more effectively and that we deliver better results. You mentioned delayed transfers of care. Currently the bulk of the delayed transfers of care are attributable to delays resulting from issues around the NHS, not social care. Those are often about access to other services needed in the community that the NHS is providing. There is work for us still to do, but sometimes the blame is laid at the door of local authorities and it is not always fairly laid there when it comes to this.

Q257 Baroness Campbell of Surbiton: Mr Shapps, housing benefit reform is a very live issue at the moment. The United Kingdom Disabled People’s Council in its evidence told us of its great concern that capping housing benefits would lead to disabled people not being able to afford their current accommodation and therefore not being able to exercise their choice of living where they want to live. The choice of where you want to live is of course a central component of Article 19 and independent living. Has your department considered the implications of the capping of housing benefit, particularly in relation to the Government’s Article 19 responsibilities?

Grant Shapps: Housing benefit is a DWP lead, but because it has “housing” in front of it I often end up speaking to the subject. The answer is yes. The DWP undertook an impact assessment that outlined these issues and has been discussed already. To be completely clear, I do not believe that anybody in this country has the right to live in any street they want to live in at the cost of the taxpayer, although clearly people have the right to live in any street.

I believe these housing benefit reforms are right overall, because it says that you do not end up in an advantaged situation, because you are in receipt of housing benefit, over and above somebody who is not in receipt of housing benefit. It is a question of fairness in both directions, to the taxpayer as well. There are a variety of changes, nine or ten, the £400

maximum per week one is the one that raised initially the most interest—are fair and at about the right level. As Maria has already mentioned, it means that up to a third of properties within a local housing allowance areas should still be available for any individual.

Those are all general comments about the changes. For those living with disability, there is a very large fund of £190 million—quadrupled from the previous fund—which is designed to enable local authorities, which are after all on the ground and therefore in the best position to judge, to assist people in not having to move when they have a particular reason to need to be in that area. People with disabilities may oftentimes find that they are the people for whom that fund was most intended.

Like all these things, it is a balance. I think some of the headlines have been quite bizarre. You would think we were cutting this budget in half. Not at all. In fact, the budget is £21 billion and is going up to £23 billion per annum. It is just not going up to £25 billion per annum, and that is the scale of the changes. As I say, there is nearly £200 million to ameliorate the impact on those who are potentially most vulnerable.

Q258 Baroness Campbell of Surbiton: Is there not a fear that this could inhibit their right to exercise the choice of where they need to live. It is not a question of “want”; it is need.

Grant Shapps: No more or less than for the population at large. For the population at large, from a government perspective, there is clearly a balance to be struck between the wider taxpayer and those who are in receipt of benefits. The Government, and in fact all the parties, have come to the conclusion—each wrote as much in their manifestos at the last election—that it can no longer be fair for people who are working to pay for people who may not be working in the general population but who are of working age and able to, to live in areas that they themselves cannot afford to live in.

That is the overall objective of it. However, this is a discussion about people with disabilities, and we have a particularly large—quadrupled—sum of money in order to ensure that it is exactly those people who have and deserve the support to not have to move. My particular concern is about where we have spent a lot of money, for example through my disabled facilities grant budget. I do not want those changes to be made and then for people to be forced to move from homes where those adaptations have been made at great cost, and there is disruption to people’s lives and cost to the taxpayer. That is why we have the big fund there—to try to assist.

Q259 Lord Morris of Handsworth: Do you get a lot of letters from members of the public complaining that you are treating disabled people much too generously and giving them too much resource?

Grant Shapps: No.

Q260 Lord Morris of Handsworth: So it is your judgment, your assessment.

Grant Shapps: My view is that we should absolutely focus the resources on people with disability. If these changes are to mean anything they should go to those who are the deserving in this, and it would be crazy to move around people with disabilities, for whom we have already tried to provide assistance through things like disability facilities, disability grants, adaptation.

Chair: You can open up a big debate about this, particularly about the contentious word “deserving”, which we could argue about from our particular positions on that. I am conscious that many people in this Committee would like to take you up on that.

Q261 Baroness Campbell of Surbiton: What are your intentions to monitor? You obviously feel there should not be this fear, so how are you going to monitor?

Grant Shapps: The overall policy has a number of protections in it: first, the fund that I mentioned, the £190 million; secondly, some people will make up the gap through their own resources; thirdly, even where people move within the local housing area, up to a third of properties will be available. A very large democratic system of monitoring is also available at a local level through the ballot box.

Q262 Baroness Campbell of Surbiton: I understand that, but will you be measuring the impact?

Grant Shapps: Yes.

Maria Miller: I will add in some detail, if I may, because, as Grant says, we have the policy lead in this area. I would add a couple of points about the other mitigations that we have put in place. We have not only trebled the discretionary housing payment to £190 million, but we are currently considering whether we need an exemption for people who have adapted property because of a disability. You will of course be aware of the additional bedroom provisions that we are making for people with non-resident carers, and that supported accommodation is not affected by these changes.

In particular, on evaluation, we have commissioned a consortium led by the Centre for Regional, Economic and Social Research at Sheffield Hallam University. We have commissioned it to undertake an independent report reviewing the proposals that we are putting in place now, and it will specifically monitor the issues for people with disabilities.

Q263 Baroness Campbell of Surbiton: Measuring the impacts?

Maria Miller: Yes. If the Committee would like any other details on that, I am sure I could draw them out.

Chair: I must press on. Mr Crockart, this question is for everyone, but if you do not feel you can add anything, do not.

Q264 Mike Crockart: This area leads on from housing benefit, but still looks at housing benefit. While it might be possible to accept that the housing benefit cap may not impact disabled people more than others, we have to look at the fact that there may be further impacts on disabled people that would not necessarily affect able-bodied people. We received information from the College of Occupational Therapists, for example, that if people have to move because of the housing benefit cap, they lose support services and networks. As a constituency MP I, too, have people coming to me, such as a 62-year-old Down's syndrome sufferer with Alzheimer's who might have to move because of this policy. The knock-on effects are that he will have a different GP and different carers, and that his confusion will be massively worse than it was before. We are back to where we were at the start, with cross-government working and silos, and the impact could be that we spend less on housing benefit but that he will end up in hospital. What is being done to monitor the impact of changes, particularly of unintended consequences, on disabled people?

Grant Shapps: I will comment on something that was mentioned before. Maria mentioned a tripling of the budget, and I mentioned a quadrupling. The difference is that some of the budget comes from DCLG. If you add the two in total, that is where the difference comes from. I do not know the details of that individual constituent, but it is precisely what the fund is there for. Absolutely I would have thought that it was custom-made for that circumstance. Our monitoring as a department will be through the way that the budget is being spent and used, through the usual mechanisms, and that work is ongoing.

Q265 Mike Crockart: Can I come back straight away and read one sentence from the letter from the council? When it talks about DHP, it says, “The period of award is normally for three months and sometimes six months, and is aimed at giving breathing space to find alternative accommodation”.

Grant Shapps: I might need to come back to the Committee on this in writing, but I think the confusion there is the same as the difference between the tripling and the quadrupling, which is some of the money is given with a specific purpose, and some with a more open objective. It would be better to know more detail of the case, but also to be able to come back to you with some of the detail of the corresponding schemes.

Maria Miller: Just to reassure you, our impact assessment looked at the sorts of issues you are talking about, and we recognise what you are talking about. That is one of the many reasons why the discretionary housing payment budget has been increased so significantly—so that we can ensure that those sorts of challenges are met on the ground. It will be for local authorities, who are far better placed on the ground to understand the needs of disabled people in the community and to be able to see how they can shore up families in the way that is most appropriate.

Grant Shapps: A local authority response could be to say there is a social home that might be more available and applicable in this particular case. I am thinking of constituency cases in my own patch where somebody has moved out of the private sector and into a social home provided by the authority or the housing trust, because it was more appropriate, and got around all those issues.

Q266 Chair: On health and social care, can I begin by asking the Minister for the Department of Health and the DWP Minister about the Independent Living Fund? Do you have any plans to monitor the impact of the closure of this fund, first on those who are currently receiving grant, and potentially on new applicants?

Maria Miller: Can I set out up front to the Committee that obviously the ILF, as you all know, is a discretionary trust? It was never designed to replace mainstream care and support. It was clear that it was increasingly becoming a postcode lottery for people who were in receipt of it. There was a report to the previous Government in 2007 about the need for fundamental change. Unfortunately that was not acted on at the time, and it left the coalition Government picking up on the issue post the general election: hence the decision that was made first to suspend the fund and then to close it.

We are absolutely clear that people who are currently in receipt of payments under the Independent Living Fund will continue to receive absolutely the level of support that they would expect on an ongoing basis to 2015. Obviously beyond the next spending review none of us sitting here can give any further commentary. I think that the additional £2 billion that the Department of Health has put in goes a great deal of the way to recognising the need to make sure that funding is available for individuals who will now no longer have access to the Independent Living Fund.

In terms of monitoring access, because it is a discretionary fund individuals did not have any particular prerequisite to go forward and to apply to the fund; it came down to the area in which you lived for a great deal of these.

Q267 Lord Dubs: My first question is about personal budgets. How are you measuring the extent to which personal budgets are enabling disabled people to have choice and control over how their social care needs are met? Are you satisfied that this policy is making a contribution to the Government’s Article 19 obligations across all groups of disabled

people, including those who in the past have been underrepresented among those receiving correct payments?

Paul Burstow: Thank you very much for the question. I referred earlier to the report published by In Control in May, which set out its most recent evaluation of outcomes for people with personal budgets, and drew some quite important conclusions about the essential need for co-production in the way in which the budgets are used to deliver against agreed outcomes. That word is particularly key in the development of the policy. We have, as a department, in our Vision for Adult Social Care, which we published last year, set a target for extending access to personal budgets to all those who are eligible by 2013, and that would mean moving from the current figure of about 340,000 receiving personal budgets, including direct payments, to over 1 million people receiving them. In our engagement with colleagues in local government, we are very struck by how they do not see this as an end in itself. The end is a much more personalised outcomes-orientated approach to the delivery of services that really does go to the heart of delivering Article 19. That is the approach we are taking.

Q268 Lord Dubs: My next question is about the postcode lottery. We have been told there is a postcode lottery in adult social care. This is not only a question of different levels of resources, and thus different eligibility, but different attitudes in understanding independent living. Do the Government intend to take steps to prevent the situation whereby disabled people's access to Article 19 rights varies according to where they live?

Paul Burstow: This goes to the heart of the reform agenda that we have for social care, and it is one of the inherent challenges that go right back to 1948 with the National Assistance Act. Central government has never had an overarching responsibility for setting national eligibility or for setting an overall direction for how individual local authorities deliver their legal obligations. In the last 12 months we have had reports and recommendations from the Law Commission on how we reform social care law, to make it both clearer and more orientated around outcomes.

We have also had recommendations from the commission on funding of care and support, which has recommended that we examine greater consistency around eligibility. That is something that the Government are considering at the moment. We are engaged in a dialogue with the sector about how we take reform forward. That will lead to a White Paper, which will give answers to the Government's approach on funding, law reform, portability, and eligibility next April.

Q269 Lord Dubs: Do you have enough powers to persuade or influence local authorities? Short of ring-fencing certain sums of money, what can you do about local government?

Paul Burstow: In resourcing for social care, as a result of the current spending settlement we agreed that funding for social care support would go in two ways, predominantly through the formula grant, which DH has provided additional resources for to support social care, but also by requiring the NHS to make specific transfers to its social care partners. By the end of this Parliament an additional £2 billion a year will go in via the NHS. In that particular case, while it is not a ring fence in the traditional sense that you might have thought of in the context of local government, it does mean that NHS and local government colleagues have to talk about how they are going to spend that money on social care activities that also support the NHS. From the feedback that I had at the NCAS conference last week, it is working well and driving new relationships and more integrated services.

Q270 Lord Morris of Handsworth: The term "independent living" is very much misunderstood. Do the Government have any plans to increase awareness about what

independent living means to people in a residential setting, about the role of service providers to deliver disabled people's Article 19 rights, and how to deliver such rights?

Paul Burstow: The beginning to that answer is that it is hardwired into the way in which the CQC is to discharge its duties. The CQC has, again, the overarching obligations around both human rights and equalities duties. It is then given force and effect through the regulations that have already been laid. Specifically, requirements under Regulation 17 of the Health and Social Care Act 2008 require providers to “make suitable arrangements to ensure the dignity, privacy, and independence of service users”, and to ensure “that service users are enabled to make, or participate in making, decisions relating to their care or treatment.” We would expect the CQC, as part of its ongoing work around inspection, to be making sure that they are satisfied that those standards are being met.

Q271 Lord Morris of Handsworth: Do you think that that is understood on the number 36 bus?

Paul Burstow: Some interesting work has been done recently between the CQC and the Equality and Human Rights Commission—

Q272 Lord Morris of Handsworth: Is it a duty, or at least a moral responsibility, to raise awareness of exactly what it means and what obligation it carries?

Paul Burstow: Yes, absolutely it is, but you also have to be clear about what the mechanisms are to translate that into activity and to deal with areas where there is failure occurring, and that is the role of the regulator.

Q273 Baroness Berridge: Mr Burstow, this question is directed at you and is about Winterbourne View. I suspect you expected this, but what steps have the Government taken to ensure that the human rights of adults living in such establishments are sufficiently protected by the present legal and regulatory framework? Are you satisfied that the current commissioning arrangements are compatible with the obligations under the convention? Are you confident that the framework within which these are commissioned and regulated is sufficient to promote and protect disabled people's rights?

Paul Burstow: The answer to the question about commissioning and whether I am satisfied the arrangements are compatible is definitely yes. If I am then asked whether all practice is compatible, I would have to say no. The evidence is very clear from what was depicted on our screens when “Panorama” broadcast its programme, from what the CQC has subsequently found from its further examinations of other Castlebeck facilities, and the ongoing work that it is undertaking to look at other facilities providing services for people with learning disabilities. What happened at Winterbourne was totally unacceptable. The Government's response to it is co-ordinated. We are in the midst of a criminal prosecution process, which hampers us in being able to say or do much publicly. We have made it very clear to the NHS, which has the lead commissioning responsibility in this area, along with its social care partners, that it needs to draw lessons from the serious untoward incident inquiries that it is already doing for its practice. It needs to make those changes as we go along now and not wait for the Government to publish an overarching set of conclusions and actions, which we will do in the early part of next year.

Chair: I have two final questions on employment. The first is to Mr Crockart, and it is specifically to the DWP Minister.

Q274 Mike Crockart: Employment is a key element to independent living, but disabled people continue to suffer particularly high rates of unemployment, especially among those

with mental health support needs. There is a lot going on with the Sayce report, but what action will the Government take if the employment rate among disabled people, particularly among those with mental health support needs, shows little improvement?

Maria Miller: As you say, work is a priority for us, for disabled people and non-disabled people alike. What is very much hardwired into the Work programme is the ability for us to be able to target certain groups of people who need particular help and additional help. We know that it can sometimes, in some cases, take more time to help particular groups of disabled people into work. All the evidence suggests that people with mental health problems have particular challenges in getting into work. The way the Work programme is structured means that we can particularly pick up on those individual groups and make sure that we remunerate the providers of the employment support in the right way, so that they can work with that group and ensure they effectively get not just into short-term employment but into long-term employment, which is what can make a real difference.

That is one way we are addressing the issue, but the other way we are addressing the issue links back to the Sayce report. You will know that at the heart of what Liz Sayce has said in her report is the importance of reprioritising resources to make sure that we are supporting not institutions but people. One of her key recommendations is to double the amount of people who are supported through Access to Work from 35,000, so that we can support more people effectively into employment through that mechanism. That, plus the Work programme activity and the mental health strategy, which I think we talked about a bit earlier, will work to highlight the need to support that particular group of people. I can assure you that my colleague, the Minister for Welfare Reform, in particular is working very hard on that area, through some of the pilots around the Fit to Work scheme.

Paul Burstow: Can I just add two reinforcing examples, which support that programme of activity? One is that, as part of the mental health strategy, we announced, a couple of weeks ago, an investment over the next three and a half years of £16 million in support of Time to Change. Time to Change is a charity-led anti-stigma and discrimination campaign that, as part of its activity, goes into the workplace and helps with addressing some of those issues. It already has significant buy-in from a number of employers, which is a key way in which we can lower some of those barriers of prejudice to access to the workforce.

Q275 Mike Crockart: Just as a quick follow-up, these are marvellous plans, but do you have a timeline to monitor whether this is having an effect?

Maria Miller: We monitor employment levels on an ongoing basis. We have figures coming through monthly. It is absolutely critical to look at the problems that disabled people have getting into work. Half of disabled people are not in employment, a significantly higher figure than for non-disabled people. If we are going to put in place all the reforms that we have around attitude to work, judging people for what they can do, not on what they cannot, you can rest assured that this is being monitored on very much an ongoing basis

Q276 Baroness Campbell of Surbiton: Previous witnesses have argued that the current government policy meant that disabled people working, and living in residential care—we often forget that living in residential can work and should work—have practically no incentive to work whatever, as any income they receive over £22.30 would be taken to pay for their residential care placement. We understand that this is an issue that has been raised with the Government time and time again. In the new environment of getting certain people into work, why have the Government not yet removed this disincentive to work? Will the proposals relating to the universal credit address this particular situation? I am particularly keen to hear from Mr Burstow and Maria Miller.

Paul Burstow: Perhaps I can start by saying that there is an issue as to whether we have the right model of care in the first place. If someone is willing and able to work with support, being in a residential care setting is probably an entirely inappropriate setting for them to be in in the first place. Supported living is a model that was very much espoused and encouraged by the last Government, and this Government support it as well. Those who are living in supported living, who are able to engage in a full range of life's experiences, including work, are of course not covered by the regulations that govern the use of a person's resources in a care home.

My view, which goes back to the Winterbourne question we were asked just now, is that just as there is an appropriate challenge to be made about why it appears that, despite consistent policy positions, commissioners have not commissioned the right services—and that is what we are looking at in the review we are doing at the moment—one of the challenges with commissioning responsibility in this area that we need to be putting, and which, as a Minister, I put to my colleagues, is: are you commissioning the right model? Do not hide behind the regulations that apply to a particular setting that in many cases would not be appropriate to the group of people that you are describing. That would be my first approach.

The second answer to this relates to the recommendations that we are currently considering from the Law Commission around reform of social care law, which makes a number of important recommendations, not least that we need to look at how we extend personalisation into residential settings, including the applicability of personal budgets and direct payments. We are looking very carefully at how that might work through, and that would clearly have some quite profound impacts on the way in which the current personal expense allowance regime operates. We will be reaching conclusions and publishing those in a White Paper next year.

Maria Miller: Improving work incentives is absolutely a part of what universal credit is all about, and it removes the risks that a lot of people who have high exposure to benefits can face when they move into work. The DH is also looking at how earnings are taken into account as part of calculating charging for residential care, and we will continue to work with DH and indeed lots of other parts of government as we move forward with universal credit. Our intention is absolutely simple and straightforward: to make work pay, especially for people on low hours, and to make it pay for anybody. We are continuing to work with whomever across government to bring that about.

I just want to make sure the Committee is aware that residential care residents have full access to Access to Work, Work Choice, and the Work programme. Indeed, a number of residents are residential care home residents who already participate in the Access to Work programme, which plays to the noble Baroness's point.

Q277 Baroness Campbell of Surbiton: That does not really answer the question, which is: will the proposals relating to universal credit address this particular situation? This individual who came to give evidence has been trying to get out of residential care for 15 years. He has had particular access to direct payments—all the things that personalisation addresses—yet he is still waiting to work. Will he have to wait another 10 years, or will it be addressed through universal credit?

Maria Miller: just to be clear, universal credit does not address the issue of disregard around earnings for people in social care settings; that is something the Department for Health deals with.

Paul Burstow: In answer to the question, the recommendations made by the Law Commission, which are about personalisation, the system being organised around outcomes, and specifically residential care moving to a model that is around personal direct payments

and so on, open up the opportunity to look again at the current charging regime and how those things work. I am not in the position to announce a fully formed policy, because that is what a White Paper is for, that is why we are currently engaging through our Caring for the Future process, which is looking at personalisation. We will obviously look very closely at the recommendations this Committee makes in the context of the conclusions and recommendations in our White Paper.

Chair: Thank you very much for coming today and answering our questions. One or two other questions will flow from the evidence session today and I hope we can write to you, if you are happy with that, to pose some more questions. No doubt if I draft the letter one of the questions will include the word “deserving”.