

# **The Right to Control consultation launch**

## **Conference report**

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London Marriott Hotel  
Regents Park

Commissioned by



Office for Disability Issues

HM Government

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### **Summary**

The event, attended by over 100 delegates (disability opinion leaders, organisations of and for disabled people, public sector commissioners, provider organisations), was positively received and evaluated.

There was strong in-principle support from both speakers and delegates for the Right to Control. Speakers referred to the Right to Control as 'a passport to active citizenship' and 'restoring my rights as a human being'. Some used phrases such as 'bring it on'. Most commentators from the floor made positive comments. Many issues were raised on specifics, some challenging, and delegates seemed keen to engage in the substance of the consultation.

The major comments raised were as follows:

Working together at national and local level (co-production) results in better use of public money, better outcomes and better responses to disabled people's aspirations.

The shift of power from State to citizen involves a significant shift in culture, which challenges all involved (commissioners, providers, disabled people themselves).

It requires a major shift from a block contracting strategy to a market driven by individual choice – which has very significant implications particularly for employment programmes.

The goal should be a comprehensive, self-directed support system across different funding streams. 'People's lives can't be split up into segments which suit government departments' as one person put it. Funding streams people were keen to include in the Right to Control were Access to Work, Workstep, Disabled Facilities Grant, Independent Living Fund and Community Care funding. Also important were housing, health and financial literacy/independence.

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Independent advocacy, information and imaginative peer support need to be focused on new opportunities, like self assessment, and are essential to make the Right to Control work. Participants noted they should not be funded from individuals' care allocations. One stop information points and support for user-led organisations across the country are important ways to achieve this and a coherent national approach is needed to stimulate this development.

Support needs to be tailored to differing needs, including people with different impairments (eg people with fluctuating conditions, learning difficulties, neuro-diverse conditions), from different communities and people living in rural and urban areas.

Work is needed on legislative frameworks for public services, to enable individuals to take risks where they are able to do so – without an excessive emphasis on public service liability. This emphasis creates incentives for the services to be risk averse and to maintain state control. A balanced proportionate approach to risk is needed, within a human rights framework.

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### **Introduction**

'The new legislation is a one-stop shop for empowerment, seize the moment!' (David Stocks, mental health service user)

RADAR hosted the launch of the Right to Control Consultation on Thursday 11 June 2009 to encourage a wide range of opinion formers in the disability sector to engage in the consultation and to build awareness of the potential impact and implications of the Right to Control. The launch was commissioned by the Office for Disability Issues in the Department for Work and Pensions.

The launch was well-attended, with over 100 disability opinion formers, national and local organisations of and for disabled people, public service commissioners and providers from the private, third and public sectors.

The launch was chaired by Liz Sayce, Chief Executive of RADAR. Speakers included:

- Secretary of State for Work and Pensions Yvette Cooper MP
- Baroness Jane Campbell
- Minister for Disabled People, Jonathan Shaw MP
- Steve Mason, A4E
- Sadaqat Ali, Ethnic Deaf UK
- Lorraine Gradwell, Breakthrough UK
- David Stocks, mental health advocate
- Ruth Scott, Scope
- Mary Helson, Office for Disability Issues.

The Right to Control is designed to contribute to the government's goal to achieve equality for disabled people by 2025. It will offer disabled people the right – if they wish – to control certain support services, thereby shifting power from the State to the individual. Provisions for the Right to Control form part of the Welfare Reform Bill 2009.

The aim of the day was to launch the consultation, invite initial feedback on how to make the Right to Control work most effectively and encourage people to engage in the consultation processes taking place over the summer.

The report which follows is a summary of the key discussions. For a full transcript please go to [www.radar.org.uk](http://www.radar.org.uk).

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### **‘How can we make the Right to Control real?’**

‘The state will provide resources, but it is the disabled person who will decide how best to use these resources to meet his or her needs. This is what the Right to Control is all about.’ Baroness Jane Campbell.

**Liz Sayce** as Chair opened by saying:

At RADAR, we see the Right to Control as a leap forward, because we have long argued that for disabled people to have real control over services and our lives, legislation is required. We are delighted that the government has listened to that message and worked with us in developing this proposed legislation.

The basic idea of the Right to Control is very simple. Instead of getting what you’re given – and liking it or lumping it – you would be told upfront what resources are available to you and you can then think how you want to use those resources to realize your dreams. Your ambition may be about getting into work or gaining new skills – and there are many things that could help. A member of the Right to Control advisory group said recently that she has decided that what will help her most with the panic attacks she gets when travelling to work is to have a personal sat. nav. device – so she can be confident that she won’t get lost. It’s about being imaginative.

The event today is a first chance to think about what the Right to Control might mean and how to make it deliver effectively for all disabled people. We shall be airing key questions like what funding streams should be included (things perhaps like Access to Work, the Independent Living Fund, Disabled Facilities Grant and more), how are we going to make it easy for disabled people to exercise the Right to Control, what information and support are we going to need, what are the rules and barriers that could get in the way – and how can we overcome them.

Legislation for the Right to Control is going through Parliament. This is a very real consultation. The government is clear that the answers to all the questions above are not yet there. Our aim is to come up with workable ways forward together.

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But today is just a taster. We hope you will want to get involved in the consultation over the summer – through more events, a consultation toolkit and more.

For RADAR, our interest in this whole agenda is that we want to see people living with ill-health, injury or disability able to have more power in our lives and throughout society.

We shall also be celebrating the very best practice in independent living – enabling control and choice – at our People of the Year awards in November. Nominations are open.

And I would now like to introduce Baroness Jane Campbell, who wheels the tightrope of being both a cross-bench peer playing a leading role in the Lords and the Chair of the Right to Control Advisory Group.

**Baroness Jane Campbell** opened by saying the Right to Control is ‘not about being consulted, not even being involved, but being in control’.

If you feel out of control, it’s impossible to think, act and feel good about yourself. Being able to control your life on the other hand gives you freedom to make choices and make plans. For me, the Right to Control is the passport to active citizenship for disabled people.

It has been a very long journey to get to this point. As someone who has been on that journey for 30 years, it’s been long, it’s been hard, but here is one of those milestones that I think will enable us to take control.

I’m afraid it is only those eligible for state resources for their support who will have this Right to Control.

The legislation is in Parliament now and I am working with others to propose ways to make the Right to Control even better.

I’ve always fought not for going it alone, but for working in equal partnership with the State. I envisage this partnership continuing during and beyond the consultation. The state brings the resources that society has decided to make available. Disabled people bring expertise about how best to meet their needs. Together, we will agree outcomes.

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We need five important things to make the Right to Control a reality:

- 1. We must guard against a policy that is understood at a national level but doesn't translate into real changes in disabled people's lives and opportunities.**
- 2. Disabled people will need to know and believe they have a Right to Control. Information and advice needs to be readily available. In turn, public agencies need to make it a reality. Jobcentre Plus, local authorities, voluntary sector organizations and others need to inform disabled people of their Right to Control and how it can work in practice.**
- 3. We will need a redesigned system where you only have to go to one organisation to find out what level of resources you are entitled to - not as is currently the case one place for supported work, another for a supported home, and yet another for certain types of equipment.**
- 4. We will need a clear separation between deciding how much you are entitled to and how best to meet your needs. We know resources are finite and that the Right to Control is not about changing eligibility criteria, but we have to free disabled people to decide how best to use the resources that are available. If money is going to be very tight over the next few years, disabled people will need more than ever the Right to Control every penny of their allocation. Our freedom to live a full life will depend on making the most effective and efficient use of the resources available.**
- 5. Fifthly, the environment in which we take control needs to be supportive and empowering, especially for disabled people who have never expected to be in the driving seat. If people want help with drawing up their support plan then it must be readily available. Disabled people will also need to have genuine choices about how to use the available resources. This requires a thriving disability-led sector – and it means that service providers have to listen to what disabled people want and redesign their services accordingly.**

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Finally we need those that are implementing the Right to Control to understand that this is not just about direct payments. Yes direct payments will be part of this, but this is about controlling everything that enables you to be an active citizen: services, equipment, maybe a day centre where a group of people will transform their centre into something completely different.

If this is done well, it has the potential to change forever the relationship between the state and the individual disabled person. It will give us the right to determine our own destiny. It will give us freedom to take risks, and it will also give us freedom to make mistakes, because making mistakes is part of becoming in control.

Only if we have all those ingredients, I believe, will we have the true opportunity to achieve full citizenship.

**Steve Mason**, from A4E, said that he represented both a provider perspective and a disabled person's perspective.

'I'm partially sighted, but I also have a significant mental health condition. Only two years ago, I was told by a psychiatrist that I was the only person he knew with my condition that actually managed to hold a job down. That's not down to me, that's down to the people around me, my employers, peers, family and people like you who have supported me over the last couple of years. I have gone from lying in bed not being able to open my eyes to standing in front of you people and making a fool of myself. So it's really good, thank you.'

Steve Mason argued that the right state of mind needs to be created for disabled people to use the Right to Control, to enable people to 'choose to choose'. People need to know they have the right to choose. We need to get this message across – relatively quickly.

He himself has benefited from choosing his own therapy – being fortunate that this is paid for privately by his employer.

'When I think about the number of people over the years that I've heard say, 'My doctor says I'll never work', or, 'oh no, I will never be able to work again'. It's embedded into people. We need to get rid of this can't work nonsense.'

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We need to work with GPs so they encourage people to take control – rather than just telling disabled people that they will ‘never work again’. With the right attitude and support, disabled people can start working.

We need to ensure systems work well for people with fluctuating conditions.

We need swifter decisions – for instance on Access to Work. And disabled people need access to more than one expert, so disabled people can be fully informed. It is important that Disability Employment Advisors and Pathways providers are able to signpost people to the sources of advice and support.

We should consider not talking about ‘disabled people’. We are all people with aspirations and dreams.

And we need to challenge the people who don’t offer control or believe in people’s potential. (Steve illustrated this vividly by reference to slapping people about with a fish!)

### **Discussion**

What happens when the individual and the service provider don’t agree? How is agreement going to be reached between a disabled person and service provider?

**Steve Mason:** the way to overcome this is to get disabled people and professionals together, to create a better understanding.

**Baroness Jane Campbell:** There will be times when service providers and disabled people don’t agree – but the Right to Control will help disabled people have an even footing with the service provider. It is a process of negotiation in which compromises will sometimes have to be made. Let me give you an example:

Recently I had a long performance trying to get hold of a new mattress and I was offered this all singing all dancing bed costing £3000 and actually what I wanted was one off the Internet costing a few hundred points because it was just like the one I had and it met my needs. They said no, you must have this one, you will be free from bed sores for the rest of your life and I cannot authorise the cheaper one, because I have evidence that you will get a pressure sore.

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I raised evidence from my own life – no pressure sore problems with this mattress – and I had to bring forth a little bit of persuasion, like would the PCT want to know that you want me to waste over £2000 of the NHS's money. Then I said that anyway, their recommended mattress would mean I would need to raise myself above my husband by 1 foot so how on earth were we ever going to have sex again? At that point they began to take notice and we talked. We won't always agree, but at least this Right to Control will raise our voice to align with that of the provider'.

**Delegate:** Disabled people need access to independent advocacy – there needs to be someone to support the individual, an arbiter between the service provider and the individual who can offer support.

In cases when an agreement cannot be reached it is important that there are alternative options available – so new options can be considered.

**Baroness Jane Campbell:** Information and training need to be available for disabled people for the Right to Control to work and it specifies in the White Paper that advocacy will be readily available for disabled people so that they are supported and informed about the Right to Control and the way it works. Amendments to the Bill are focusing on the necessary framework for support.

**Delegate:** The Right to Control will mean different things for different disabled people, in different parts of the UK. For instance, in urban areas there are probably more services available for disabled people. Whereas in rural areas there needs to be more help for disabled people. For people with learning difficulties to be 'in control' – it may take time and support to understand what being in control actually means.

**Delegate:** There are duties of care that we as local authorities have, that can conflict with individual's choices, because we are obliged to take responsibility for risks. Legal responsibilities need to be reviewed in order to ensure the Right to Control is effective.

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**Liz Sayce:** the idea that disabled people are a risk, or have to be protected from every possible risk or that disabled people themselves pose a risk needs to be challenged. The former Disability Rights Commission took up a number of cases – young disabled people not permitted to go on school trips ‘for their own safety’, disabled women denied independence through health and safety fears about staff lifting or handling them, mental health service users denied housing on ill-evidenced grounds that they are a ‘risk’ to others. Of course risk management is important – but there needs to be a balanced, proportionate approach to risk within a framework that protects disabled people’s human rights. We also need to clarify when the individual carries the risk of their decisions –and when it is rightly the organization.

**Delegates:** I’m disappointed that in the consultation paper, case study 4, there is mention of someone with autism- but no mention whatsoever of the kind of access needs which are likely to be things to do with sensory overload and metabolic needs. The Employers Forum on Disability did good work on dyslexia, which points out that people are likely to need a single office of their own, help with social interaction, screening out noise, materials in different colours, and basically to be in control of their environment.

In my area choice and control are working well. We need to share good practice where it is happening.

The commissioning framework could conflict with the Right to Control. If fewer providers are getting larger contracts – what choice will there be? We need to re-think the commissioning strategy. We don’t want a Tesco effect ie large monopoly providers.

Disability equality impact assessment of the commissioning process may be useful in this respect. The new Equality Bill covers procurement as well – so that may be helpful.

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### **Secretary of State for Work and Pensions, Rt Hon Yvette Cooper MP**

It is a great pleasure to be here today. I have been in post just less than a week, six days in fact, but I was very keen to join Jonathan today so that we both could come and make clear the importance of the Right to Control – and how important it is across government as well. Thank you too to Liz and to RADAR for all the work they've done to host this. And of course to Jane and to all of the others I know have been involved in the work to get the Right to Control right, to get this policy moving and to support the consultation, and the introduction of the legislation as well.

Jonathan, as you all know, has obviously had meetings and discussions with many of you over recent months about the work both on this area of policy, but also on the wider policies affecting disabled people, and I also see it as a hugely important programme of work.

For me, the principles that underpin the Right to Control are vital-principles around independence, around people having control of their own lives, being able to take choices, about greater equality for disabled people, about making sure that people have a say over the way in which services are provided.

The importance of these things struck home to me in a constituency case that I was dealing with over the last couple of months, which was about a disabled man who came to see me. He came with his family because he had been told by the medical professionals that he needed a new wheelchair, a different kind of wheelchair, because the one he had affected his health. The one they gave him he was deeply unhappy with, his family were deeply unhappy, it was too heavy for his elderly parents who were his main carers and it meant particularly he couldn't go dancing. He went to dancing sessions once a week, the most important thing in his life, his opportunity to get out and do things and he particularly loved music. It was a hugely important part of his life, and when he was no longer able to continue, that had a terrible effect on his health. He was feeling depressed and his health was suffering, and it took two months, even with the MP getting involved, to try to get some movement because the medical professionals' approach was: 'this is the kind of wheelchair he needs and this is what we're prescribing.'

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In fact after we had been involved and had had a whole series of discussions, they found a way in which they could modify his old wheelchair and adapt that and now he can go dancing again and it has transformed his life. The family came to see me again just two weeks ago and there was a transformation because he has got the services that actually work for him and work for his family and that is having a better, more positive impact on his health than anything else.

It was such a striking example of the way in which disabled people and their families will know far more about what the real barriers are that people face - whether it's being able to work, whether it's being able to do different things in the community or the way in which people live their lives.

That's why I think this principle of control is so important. But also the principle of us developing the policy together, of government working with disabled people to develop the policy in the first place and to get the detail right as well. You could call it co-production. I think that's the sort of odd word that people wonder what it means unless they're actually involved in, but it captures the principle that I think is so important.

So we are launching the consultation on the Right to Control and we want to get the practical details right. It is important that we do this in a way that really supports people across the country and doesn't end up creating new problems or creating problems for other people as well, so that we can actually make it work in practice.

What we want is your views on how we make this work, your views and thoughts on whether we've got it right, whether we've got it wrong, about what kind of funding streams should be involved in this, what are the mechanisms needed to make this work in practice at local level, what skills and training people need at local level and what kind of support people need in order to be able to make decisions as well.

I think this is a critical part of pursuing greater equality for disabled people. We now have disabled rights legislation making a commitment to equality for disabled people by 2025. The adviser group has given a voice to disabled people at the heart of government. We've pushed on with the Independent Living Strategy, which itself was developed working with disabled people as well.

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We've earlier this week ratified the European convention on rights for disabled people, and I think we have come a long way in recent years, but of course we still have a long way to go.

I know from the example of the family I was talking to, we still face discrimination, we still face difficulties and we have got to keep striving and working to tackle the problems that remain – which is why I think this is such an important measure.

Interestingly, I think the principle of the Right to Control is tapping into something that is not just about disabled people. It's actually building on the way in which government should be giving more power to individuals in more areas and the way in which we should have more ability for people to take control of their own lives, while the state, the government and public services play that supportive role.

I also think it's particularly suitable and right that in fact it's here, in support of disabled people, that we are pioneering a principle that we should be applying much more widely. To actually make such a focus of it as part of support for disabled people is part of dealing with those wider inequalities, and wider discriminations as well.

It is a principle we should apply far more widely and I know it's something that Jane and others have championed more widely in other public services too.

So we will be launching the consultation. We then want to get the trailblazing local authorities going as well. What are the challenges, what works, what doesn't work in practice? That's where your expertise and advice will be critical.

We've tried to respond to different views that have already come forward, but I'm very clear about this, we know we're going to need to make further changes and amendments during the consultation as well.

There's going to be a toolkit produced to help organizations, groups and disabled people to gather views. So we're going to be sending that out shortly, but I just wanted to say in conclusion, to give you my commitment and Jonathan's commitment to working with you to get this right, to be able to take this forward to make sure that we can really make a difference, and frankly to transform people's lives across the country, because that in the end is what it's about.

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It's about disabled people in every corner of the nation having better opportunities, better chances, better control of their lives, but not just that, better control of their lives so that they can do more with their lives and seize all opportunities that are available to them.

So thank you very much for coming today. Thank you very much for all the work you've done so far on this and I look forward to working with you on this and on other areas of policy in the future as well.

### **Thank you very much.**

**Liz Sayce:** Thank you very much. We have been really pleased by the 'co-production' or partnership working between disabled people and government in developing this policy. It's also very pleasing to have both the Secretary of State, leading on this policy area, and Baroness Jane Campbell who has pioneered this work and playing a leading role in the Lords on our platform. We believe that working together results in better policies – better use of public money, better outcomes and better responses to disabled people's aspirations.

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### **Responses from Sadaqat Ali, Ethnic Deaf UK and Lorraine Gradwell, Breakthrough UK**

Lorraine Gradwell began by introducing her organisation, Breakthrough UK – a disabled people’s organisation in the North providing employment services and support for independent living.

Lorraine welcomed the new Minister and welcomed opportunities for greater financial analysis looking at cost benefit analysis and cross sector benefits of the Right to Control. These are areas where relatively little work had been done and more is needed.

The Right to Control is the last civil rights movement, signalling the full participation of disabled people in society. It is sad in some respects that legislation is needed for rights that other citizens already have.

The challenge of the Right to Control is welcome – a challenge for all involved: for local and national government, for service providers who will have to deliver on contracts with individual disabled people rather than just having a block contract from the local authority, and a challenge for those who commission services.

It is also a major challenge for disabled people to test the boundaries of the Right to Control and make it work. Lorraine highlighted some examples that she had experienced.

A couple of years ago I needed a new power wheelchair, so I rang up Access To Work and they wanted me to fill in a long form, go and see my GP, go to the local assessment centre. I said, ‘All I want is a new wheelchair, one the same as I’ve got, but it’s falling apart and I want a new one, can I not just go and get it?’ They said yes, so that was good.

I needed a new bath seat. The local authority said, ‘Six months/ eight months assessment.’ I said, ‘I’ve seen the one I want, it’s in Argos, I have money in my direct payments account.’ ‘No, you can’t do that, you need an assessment’. Eventually I said: ‘On this date, the week before I move in, I’m going to go and buy it. If I could have your permission, great, but this is what I’m going to do’. After that I got permission which was good.

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Most recently the local authority have delivered to me a care plan which says I can have an hour every morning to get me out of bed, get me showered, pat me on the head and send me off to work. The fact I already do this for myself is apparently not an issue. They also said: we can't guarantee what time people can come and do that. So did they come at 5.30 this morning when I got up for the train from Manchester? I don't think so. But if they did help me get up each day I would get used to it – lose some of my independence – and it would be a poor use of public money.

The challenge is don't settle for second best. Let's go for the services that work for us, not the ones that don't work for us. Bring it on.

Sadaqat Ali began by outlining the origins of his organisation Ethnic Deaf UK. It was founded two years ago, based on the recognition that BME groups and deaf people – adults and children – needed extra support. These were groups that had been forgotten.

Now was a time for change, a time for deaf people to build up better support and networks. Sadaqat asked that this group be involved in important consultations and that their views taken on board.

Sadaqat stated that everyone has experienced discrimination and it was important to work on the basis of empathy with everyone – with government and policy makers to ensure a positive future for all of us.

Sadaqat outlined a very important example in the form of deaf people going to visit the doctor. Many deaf people feel oppressed, as many barriers are present. The receptionist or doctor or nurse normally cannot sign; the individual may not know when his or her name is being called and, in the consultation, may not understand what is being said about their health. This all leads to the patient not receiving a satisfactory diagnosis.

Sadaqat emphasized that it could be something as serious as cancer, so it is vital that sign language is available so deaf patients can access information and accurately understand their own situation and circumstances.

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Sadaqat said it was crucial that information is clear and accessible for everyone, in different formats such as visual formats, so deaf and disabled people can understand like everyone else.

This requires that stakeholders work together to create a better life for everyone. The Right to Control could help individuals to specify and control what they need, in the interests of their health and well-being.

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# **Questions and Comments to Rt Hon Yvette Cooper MP and Minister for Disabled People, Jonathan Shaw MP.**

### **Question**

The importance of advice and advocacy services. Such services will be critical if the Right to Control is to work. However, these services are patchy, on unstable financial footings and have bleak futures. Can we have a guaranteed, coherent national strategy?

### **Question**

To help individuals assist their relatives in obtaining care. Sometimes the individual's choice means they are left isolated – when they may not be able to choose. We need to involve relatives as well.

### **Question**

There is an important issue regarding culture and the shift of power. As a parent of someone with a learning disability the policy is working very well for us. There are difficulties with it, but there are more bonuses and successes than there are difficulties, so it can be done. But there is a big issue with regard to culture and the shift of power – and the shift of resources. If we are commissioning outcomes that are person centred for the person, then that should determine what contracts we put out to any provider and what individuals can buy should they choose to use the money themselves. We have to do that – and get away from the 'can't do won't do' culture that still exists.

**Secretary of State:** an effective and competent advice and advocacy service is extremely important and the consultation is an opportunity to understand what exactly is needed.

Without commenting on individual cases, it is important individuals have the right support for their circumstances.

On the issue of culture, Ms Cooper said she believed sometimes you need to have a legislative change in order to change the culture. However, legislation will not do this alone – which is why intensive work is being done across the country.

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**Jonathan Shaw:** Having an advocacy service will be absolutely central. If you do not have the capacity to access agencies that have the funding streams, the Right to Control will not work effectively so building capacity in communities will be vital.

Mr Shaw raised the example he came across recently of a coalition of disabled people in Essex, where advocacy is linked to sustainable models of funding. This will be crucial

On the topic of the shift of power moving to the individual, the relationship between central and local government is a mature one and local government generally wants to see the Right to Control delivered.

### **Question**

From the perspective of a local authority in Bradford – how to engage councils more effectively?

### **Question**

The need for housing to be made more accessible and affordable – housing is critical to the Right to Control. Housing benefit rules create barriers

### **Question**

How can information about resources in a local area be made more accessible particularly to those who are isolated; and how can a service be made available in an area if it does not exist in that locality?

**Secretary of State:** One of the purposes of Local Area Agreements is for the local authority to work with health, police, other agencies and the voluntary sector. The biggest barriers for disabled people occur when organisations do not work together. Housing is one of the most important services that affect people's lives and prospects. The government has been working to boost the standards and accessibility of new houses being built.

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On the question of isolation, there were two issues. Firstly, those who may not need day to day support could still benefit from the Right to Control and having more power. Secondly, the government was looking carefully at the variations in services and the inequalities this creates. It will be important for the Right to Control trailblazers to look at issues in rural areas.

**Jonathan Shaw:** Following the Right to Control consultation, there will be a crucial publication on the care and support agenda. This will be a vital debate on how care and support is organised around an ageing population. The agenda will need to answer questions like how resources will be targeted and how to balance competing demands. The next stage will be to look at how to simplify a complex benefits system. Individuals complain that 25 benefits that overlap is far too complicated.

He stressed his commitment to implement change and attaining the goals and ambitions outlined in the Independent Living Strategy.

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### **Workshops**

#### **Which funding streams should be included in the Right to Control?**

- Ultimately, starting from the individual's perspective, we thought we should include needs for health, housing, food, transport, leisure, education and employment – and then look at government funding streams that would support those requirements. Long-term, we seek a seamless approach
- For inclusion in the Right to Control we identified the Independent Living Fund, Community Care, Access To Work, Disabled Facilities Grant, Workstep, educational grants. We discussed Disability Living Allowance

#### **What does the Right to Control means for service providers, voluntary groups and support services?**

- We need a market system driven by individual choice – not block contracts. Currently the market is driven by volume not individual need and choice. Contracts need to be driven by the market in terms of individuals' choices – and therefore there needs to be a review of commissioning in relation to the Right to Control, including in employment programmes
- Alignment of social care and Right to Control funding streams, so the individual has a seamless experience
- Improving contracting by National Government
- Providers will need to be much more innovative in what they offer. And there should be a role for specialist providers eg provision of BSL. We need to learn from the individual budget pilots and the Office for Disability Issues should take a lead in identifying positive models and spreading them
- There are potential conflicts of interest if providers also run advocacy services. We need independent advocacy

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### **Helping people to use the Right to Control**

- Independent advocacy is essential
- Targeted information at the right time to meet an individual's need. Access to peer information and support – because learning about shared experiences and what others have found helpful in the past is really important. Information early about where to find advocacy is important; as is information on what to do if your requirements change
- Confidence – both disability confidence amongst providers and confidence of service users. Encouragement and support so you are confident you can move from being a victim of services to a citizen – making the jump to using individual support
- Engagement of disabled people – not only representation on local partnership boards but also engagement through the public sector duty
- Stronger enforcement of the Public Sector Duty, with more resources going into enforcing legislation and enabling public sector organisations across the country to engage effectively with disabled people
- Support and training to enable you to exercise the Right to Control – for instance, training in self assessment, book-keeping, employer responsibilities, workforce recruitment and retention – if you plan to employ personal assistants. To reduce costs this awareness and training might be done through circles of friends, peer support, road shows, a web-based information point. Perhaps also a service within an advocacy service – to support you with book-keeping rather than everyone needing their own accountant. This requires local organizations to have the capacity to offer support and to answer wide-ranging queries
- Advocacy and support that meet different needs. If you're transgender and you need an advocate you need an advocate from the transgender community who understands what it is that a transgender person needs. You may find your impairments are not understood in a general transgender setting but your transgender issues are not understood by general disability organisations
- Practical things to enable you to have control – like accessible affordable transport

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### **Working together to support disabled people**

- Advocacy support – self advocacy so people can control the process as much as possible
- User led services. This requires respect from non-disabled people for the expertise and capabilities of disabled people and for the role of user-led services
- Practicable formats. We would like commissioning to include organisations to provide, for example, sign language interpretation, accessible web development and Easyread production to all major organizations – like hospitals. This requires organisations skilled in confidentiality, data protection, accessibility.
- We need to map the providers of advocacy and support and then identify gaps and work to fill them. We should invite feedback and evaluate progress, involving disabled people
- All agencies need to identify the resources available and publicise how to secure the Right to Control – through GP surgeries, Citizens Advice, leaflets to households, Direct Gov website etc.
- A one stop shop for information and advice – including welfare rights, advice on finance, being an employer, seeking employment/training etc. With all information available in alternative formats and support and interpretation available where needed
- Joining up our information, and eventually having a shared assessment process across agencies – starting with self assessment and access to the different funding streams.

### **Sorting out the potential problems with the Right to Control**

- The eligibility criteria currently stop people getting what they need. Variation between local authority areas leads to unfairness. The way eligibility is set and applied needs to be reviewed
- Commissioning must be based on individual preference, not block contracts, with much more competition between providers. Commissioning needs to be about people, not just money.

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- Person-centred planning should be used to work out what a person wants, with independent advocacy to support them, not just a social worker. It's about the person choosing services rather than being fitted into existing structures
- For the Right to Control to work we need training for providers (including on how to manage the payment/finances), we need advocacy – and we need disabled people to know their rights. Otherwise these will be obstacles to delivery. Information and advocacy must be provided on top of the allocated individual budget – not cut into the resource available under the Right to Control
- Organisations need to work together at local level – including housing, which is critical.
- We need service user involvement/engagement – on everything from equipment to housing. Delays eg to getting equipment need to be removed. If service users know how much equipment costs and how much social services or health pay for it they may be able to source their own cheaper alternatives. Or health/ social services may be able to get better deals, offering more choice of equipment
- There are some specific barriers eg housing benefits and council tax benefits don't mesh with other benefits and funding streams and can be a disincentive to employment. We need alignment between health, social care and Right to Control budgets
- We need to stimulate the market and have more choice of services. At present if someone is unhappy with their provider there are often no alternatives (especially in rural areas)
- Risk and liability. We need a cultural change around managing risk. The starting assumption should be that the individual can make decisions about their own risk unless this can be shown to be not the case. We must have clear ways of showing that the liability can be attributed according to those principles in a legally binding way.
- Entitlements to support should be portable, if you move from one area to another
- We need individuals to be able to join up funding streams – otherwise getting the Right to Control will be fragmented and bureaucratic

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### **Panel discussion on the way forward**

#### **Sadaqat Ali, Ethnic Deaf UK**

Sadaqat focused on how the principles of the Right to Control could improve the services of the NHS for hearing impaired people. Research shows that a lot of hearing impaired people miss appointments – and indeed can't easily make appointments, when telephone contact is required - and are in worse health than hearing people because they find it so difficult to make appointments and to communicate effectively with their doctor. 35% of deaf people have a problem communicating with their doctors; 20% have difficulty making appointments. As a result many deaf people avoid the GP – and are more likely than others to be referred ultimately to specialists. The way forward for Sadaqat, using the Right to Control is to have greater choice – for instance, choosing to see a doctor who you find very easy to lip-read; or using technology to link up to a signing service on-line for the consultation. There would then be no miscommunication. Doctors, receptionists and others can learn BSL or undertake deaf awareness training. GPs and PCTs need to make information easily and readily available for the Right to Control to work.

#### **David Stocks**

David talked about how the Right to Control could help him. For David, the Right to Control means:

'restoring my rights as a human being'

'For decades now, people with mental health conditions have been treated as second class citizens, being passed between doctors and psychiatrists, not as a person but as the contents of a case file. I have been observed not as a patient, but as a lab rat. My opinion was neither sought nor listened to when offered. Is it not strange that a psychiatric doctor who has but a few minutes of time to spend with you doesn't value your input, input gained from a lifetime's experience, not just a few minutes leafing through your notes?'

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The combination of medication that suits the individual and psychological therapy – both of which David had asked for for a long time – transformed his life and enabled him to start realizing his potential, in employment, leadership. The Right to Control makes human and economic sense.

Long term health conditions can interrupt employment. Provision of training can be made through the Right to Control and employment becomes so much more possible to those who have otherwise been denied it through their condition.

We need a simple one stop system of empowerment for each and every one of us. We need to simplify the paperwork and make it consistent across all local authorities.

‘A psychiatrist will often see a patient within so many weeks of being referred, but it is usually several months or years before their treatment begins. I want to hear that by accessing their Right to Control, a mental health patient can get the psychology they need before it is too late and they become a statistics of a more tragic kind’.

### **Ruth Scott, Scope**

Ruth addresses three points to that make choices the idea of the Right to Control.

- Fragmentation
- Stimulating the market for services
- Making sure you don't leave all this management of this new system to individuals.

For Ruth, the Right to Control puts power back in the hands of disabled people. But the Right to Control is only being extended as far as some funding streams. Social care and health services are excluded. People's lives can't be split up into segments which suit government departments. It should make it easier for people who need to use services. It shouldn't be the case that disabled people are expected to use some services conditional on being able to use others. It is important to join up these funding streams as soon as possible so that disabled people can control all of these budgets and not necessarily prove that they are entitled to different funding streams.

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The less bureaucracy and departments you have to split money into, the better

In terms of stimulating the market, it has historically been quite difficult for service providers to talk to disabled people and find out what they want. Scope as a service provider has been talking to local authorities about what disabled people want – because of the way block contracts are negotiated. This needs to change. Any business would find out its customers' demands.

Local authorities need to find out what disabled want from local services to inform commissioning; and providers need to engage disabled people. This would enable service providers to react, respond and provide the service that disabled people want.

A lot of disabled people have reported that when they move to direct payments or individual budgets, the funding they receive is not enough to cover the cost of services, or they cannot find services. The market needs to be stimulated so that there is genuine choice available.

People need to be supported. There needs to be someone to identify the disabled person's need, and support them to draw up a plan. However it is not clear who is this person going to be, who negotiates the paperwork and has to deal with the various departments and bureaucracy. This is what ODI have to look at.

It is important for disabled people to have the necessary support and information to make the best decision.

The Right to Control agenda needs to link with other government agendas. For instance, there is a lot of work going on into financial capability and financial literacy – this will be useful to disabled people to understand how to manage their money. By linking the Right to Control agenda to other agendas it will give disabled people the varied support that they need.

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### **Mary Helson, Office for Disability Issues**

‘I don’t think anybody who has been here today is in any doubt about the enthusiasm for this agenda and the recognition of how ambitious and radical it is. Jane Campbell talked about it being a passport to active citizenship, and David Stocks talked about it restoring his rights as a human being. I don’t think you get much more important than that’.

In order for power to be transferred to the state to the individual, everyone needs to work together to enable disabled people to be in the driving seat. Developing policy and commissioning services from the perspectives of disabled people means we need to make a fundamental change in how we think and talk about the issues.

So in the consultation we want to work in ‘co-production’, working together to put disabled people in the driving seat. We’re not going to work out how to make the Right to Control work without having these sorts of discussions and without all of us going back to talk to many other people within our own organizations and feeding back ideas. We have touched on vital issues today, like how to stimulate the market, the importance of advocacy and user-led organizations. We want your advice on how to tackle them. For instance, how can we best scale up the provision of advocacy and user-led organizations?

The issue of alignment of community care funding has come up strongly today. We are absolutely clear that the Right to Control trailblazers will not work unless we align with social care. Community care is far too fundamental a form of support for disabled people for us not to take that into account, and we are looking at how the trailblazers may be able to sit alongside some of the personal health budget pilots, so that in future we will be able to build a comprehensive system of self directed support.

Toolkits and funding will be available for different organizations to hold events and feed back to Government. The consultation runs until the end of September. There are other events over the Summer. And finally a huge thank you to RADAR for hosting the day.

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### **Liz Sayce, RADAR**

Going forward, Radar will be supporting Parliamentarians including Jane Campbell to ensure that the legislative framework is as good as it can be. As Vice Chair of the Right to Control advisory group, I will be working with officials to advise them on getting the next stage of the policy right – taking account of all the points made today. Over the Summer we hope to keep in touch and take account of the different comments coming back from different people, so we can help – together – build an effective Right to Control.

There are a lot of specifics to get right and a lot of challenges to face. But as Lorraine Gradwell mentioned, challenges are welcome – ‘bring it on’. Thank you very much.